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Towards the full inclusion of people with severe speech and physical impairments in the design of Augmentative and Alternative Communication software

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By

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Dedication

This work is dedicated to Alan for keeping me sane, making me laugh, being my best friend and doing the dishes every day for the final months of this work!

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This research would not have been possible without the support and assistance of my friends and colleagues in the School of Computing and particularly the AAC research team for being willing to listen to my ideas and share their insights. Thank you to you all for getting me through the past three years.

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And, most importantly my thanks to all my fantastic participants and in particular the “three troublemakers”, without their effort and dedication this work would not have been possible. This is their story, I am proud to be able to tell it.

Declaration of the Candidate

I declare that I am the author of this thesis; that all references cited have been consulted by me; that the work of which this thesis is a record has been done by myself; and that this thesis has not been previously accepted for a higher degree.

Suzanne Prior

Declaration of the Supervisors

We declare that Suzanne Prior has satisfied all the terms and conditions of the regulations under Ordinances 12 and 39, and has completed the required terms of research to qualify in submitting this thesis in application for the degree of Doctor of Philosophy.

Dr. Annalu Waller

Dr. Thilo Kroll

Photographs

Permission from research participants has been given for the use of their photographs in this thesis.

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Abstract

User Centred Design is accepted as being essential to good software design, only by involving the users throughout the development process can the developers understand what the end users really want (Sharp et al., 2007). One area which has in the past had little experience of User Centred Design is Assistive Technology, and in particular Augmentative and Alternative Communication software (Waller et al., 2005a). Augmentative and Alternative Communication (AAC) offer the possibility of being able to access communication for people with Severe Speech and Physical Impairments.

Currently Augmentative and Alternative Communication aids have a high rate of abandonment due in part to poor usability (Prior et al., Accepted). The term abandonment has been used for a variety of different definitions in AAC and assistive technology fields (Johnson et al., 2006). For this thesis, Johnson's definition of abandonment will be used; abandonment refers to inappropriate discontinuation of an AAC device. Discontinuation of AAC devices due to a move to a more appropriate device or due to the user no longer having a need for the device are not considered to be an abandonment in this thesis.

This abandonment causes frustration and upset to the user, their family and friends and their support staff (Johnson et al., 2006).

It has been suggested that by carrying out User Centred Design in the development of Augmentative and Alternative Communication aids that their usability could be improved (Waller et al., 2005a). However, there are many challenges identified in the literature as to how to carry this out with adults with Severe Speech and Physical Impairments (Prior, 2010).

This thesis describes a software development study which investigated methods currently used in software development and how they could be adapted for use with this population. The way difficulties cited in the literature when working with this population were tackled are also discussed. The study involved four adults with Severe Speech and Physical Impairments in the User Centred Development of a piece of assistive software.

The study found that with careful planning it was possible to conduct User Centred Design with participants with Severe Speech and Physical Impairments, the lessons from this study were translated into recommendations and provided to a second developer who wished to work with adults with Severe Speech and Physical Impairments. The second study found similar levels of contribution to the features of the software were found in the pilot study.

This work has demonstrated the potential for adults with Severe Speech and Physical Impairments to be actively involved (i.e. contribute a high proportion of the features) in the development of Augmentative and Alternative Communication software. A number of areas for further investigation have been identified including the differences found in usability of devices developed using User Centred Design compared to traditional methods, and also how adults with Severe Speech and Physical Impairments can be more actively included in a range of research fields.

Chapter 1. **Introduction**

> *"This is my biggest complaint about new technology. It's almost like technology manufacturers think people with disabilities don't go outdoors or anywhere that's not flat. The newer AAC devices all have LCDs nobody can use outdoors and my regular power chair can't even handle a couple inches of thick grass. These things are cramping my style."*
>
> *(Dattilo et al., 2008 p. 22)*

The above quote belongs to a 27 year old woman with cerebral palsy. Cerebral Palsy affects how a person's brain is able to control their movements, including their ability to speak verbally. She has a college degree and is fiercely independent but is restricted in her desire to be independent by the poor usability of Assistive Technology, in particular her Augmentative and Alternative Communication (AAC) device which she uses to communicate (Dattilo et al., 2008).

It is not merely the users of AAC devices who become annoyed by the poor usability of the devices. Their friends and family also become frustrated when the devices do not operate as expected, as this quote by a mother of a 20 year old who uses AAC shows:

> *"The scanning was accomplished by a head switch, and was about as slow as chiselling on stone with a toothpick. This problem was further complicated by the computer's hard drive crashing about once a week. Needless to say, desire to communicate plummeted."*
>
> *(McNaughton et al., 2008 p. 49)*

These quotes illustrate the frustration felt by end users of AAC devices and their families when the devices do not perform as they wish. AAC devices have the potential to greatly enhance the lives of people who are unable to communicate verbally, but

currently this potential is not being fully realised due to the poor usability of the devices (Waller et al., 2005a). The devices are often complicated, do not respond in the way a user would expect and are often organised in a way that is confusing to the end user. In both industry and academia it is accepted that the best way to improve the usability of technology is through User Centred Design (ISO, 2010). User Centred Design is a methodology which demands the early and continual involvement of end users (ISO, 2010, Sharp et al., 2007). To date little work has been done into how the end users of AAC devices can be involved in User Centred Design.

The original motivation for this work came out of a need to look at the difficulties faced by people with Severe Speech and Physical Impairments[1] in hospital. A software development was commissioned by Capability Scotland which would allow medical staff to find out who the patient with SSPI was. However as the author spent time in a care centre with adults with SSPI with the aim of discovering how they currently used technology it became evident that current assistive technology was not being used effectively. The author investigated the issues of poor usability and abandonment of Assistive Technology and in particular Augmentative and Alternative Communication. A review of the literature showed that to date little work had been done in User Centred Design (one of the main techniques used in improving usability) with this group of users. This led to a wish to explore this issue and the original focus (the software for use in hospital) became the vehicle for the research.

The author used a variety of techniques to work with the adults with SSPI in the software development process. The hypothesis was that despite the published view that

[1] The term SSPI is used to indicate that the people concerned have severe impairments and will have significant problems in communication. They may also have some degree of cognitive impairment which can range from slight to profound (Redmond & Johnston, 2001).

the end users of AAC could not actively participate in the software development process, they could.

By working with the participants with SSPI on the development of the software process the author produced evidence that be adapting techniques in User Centred Design it is possible to involve them in design activities.

This work resulted in recommendations for developers wishing to include adults with Severe Speech and Physical Impairments in the development of software. These recommendations were then successfully piloted by a Master of Science student.

This thesis is divided into eight chapters. Following this introduction, Chapter Two introduces Severe Speech and Physical Impairments and AAC in more detail. The chapter then discusses the issue of abandonment of AAC devices and how this may be linked to problems in the usability of devices.

Chapter Three provides a short overview of User Centred Design.

Chapter Four contains a review of the literature regarding User Centred Design and adults with SSPI. The areas of missing research are identified. The chapter ends by setting out the aims of this research, identifying the specific research questions the research activities sought to answer.

Chapter Five presents an examination of the current methods in User Centred Design that are available and their suitability for adults with SSPI.

Chapter Six reports on a case study looking at the involvement of participants with SSPI in the User Centred Development of an item of Assistive Technology.

Chapter Seven discusses the development of a series of recommendations. These were produced from lessons learnt in Chapter Six.

Chapter Eight reports on a second case study in which a new software developer carried out a User Centred Design lifecycle with adults with SSPI using the guidelines. The results of the second study using these recommendations are also reported.

Chapter Nine contains a review of what was learnt in the study and the answers to the research questions.

Chapter Ten discusses the implications of this work and areas for future research.

Chapter 2. **The Abandonment of Communication Aids**

"*Because I don't speak they think 'ah he doesn't have a mind of his own'"*

Doug, a participant in the study with SSPI

2.1 Introduction

This chapter presents an overview of Severe Speech and Physical Impairments (SSPI), with particular regard to its effect on communication. The use of Augmentative and Alternative Communication (AAC) to assist people with SSPI in communication and the different forms of AAC available are presented. The chapter concludes with an examination of problems that despite advances in technology are still prevalent in high tech AAC devices and the impact this has on the abandonment rate of AAC. It is proposed that an improvement in the usability of AAC devices could assist in reducing the abandonment rate.

2.2 Severe Speech and Physical Impairments

Severe Speech and Physical Impairment (SSPI) is an umbrella term used to describe a set of impairments that affect the motor and communication abilities of an individual (Redmond and Johnston, 2001).

2.2.1. Prevalence of SSPI

A number of different disabilities can contribute to someone having SSPI. Congenital disabilities are the major reason for children having SSPI and originate either before, during or shortly after birth (Munson and Munson, 2000). The most common congenital cause of SSPI is cerebral palsy (Larsson et al., 2009) which is thought to occur in 1 in 500 births (MacDonald et al., 2000).

Another cause of SSPI is an acquired impairment, often as a result of a brain or spinal injury from a car crash or stroke (Roy et al., 1993). The third reason is as a result of developmental delay which can result in problems with communication and mobility (e.g. Down's syndrome or severe autism) (Mundy et al., 1995, Aldred et al., 2004).

All of these causes may also result in a cognitive impairment (Wing, 1981, Hamm et al., 1993). This can range from mild learning disabilities to a profound impairment which renders the individual unable to make any decision on their own (Wing, 1981).

The number of people with SSPI is difficult to ascertain, there has been no recent empirical work done to gather data on the prevalence of SSPI (Holmes et al., 2010) and details on SSPI do not appear in the United Kingdom census (Office for National Statistics, 2011). However, the Bercow review in 2008 showed that 1% of children entering school in England have SSPI and require aids for communication (Bercow Report, 2008). This number correlates closely with figures from 1986 which put the prevalence of SSPI in the population at 1.4% (Enderby and Philipp, 1986).

2.2.2. Impact of SSPI

In order to better understand the population it is helpful to examine each of the impairments individually along with the Assistive Technology devices which are designed to minimise the impact of these impairments on a person's daily life (Robitaille, 2010).

2.2.3. Physical Impairment

The physical impairments in SSPI include problems in gross and/or fine motor control. Gross motor control refers to large general movements of limbs (e.g. shaking a leg or waving an arm) and requires the proper control of muscles, bones and nerves which must all be coordinated (Barreto et al., 1999). Fine motor control refers to small finely controlled movements such as eating, swallowing or writing. Both fine and gross motor

control rely on the brain controlling the actions (Barreto et al., 1999). When the brain is damaged this can impact on the ability of a person to carry out these tasks.

There are a wide range of motor devices available on the market to help an individual move more independently (Enders and Hall, 1990). These devices include wheelchairs, walking frames, adapted cars and scooters.

2.2.4. Communication Impairment

Individuals may experience a physical inability to speak or be unable formulate the words needed for communication (Glennen and Descoste, 1997).

Additional impairments such as sensory (e.g. hearing) or cognitive impairment can affect the receptive processing of communication (Glennen and Descoste, 1997). Receptive processing refers to how a person interprets or understands what is being said to them (Demchak et al., 2002).

2.2.5. Effect of Communication Impairment on Quality of Life

Without access to communication it is incredibly difficult for a person to be able to share their needs and preferences:

> *"I know what it is like to be fed potatoes all my life. I hate potatoes! I know what it is like to be dress in reds and blues when my favourite colors are mint green, lemon yellow, and pinks. But then, who knew that but me"* (Paul-Brown and Diggs, 1993 p. 140)

Given how difficult it can be to express even basic needs it is perhaps not so surprising that adults with SSPI often experience social isolation. Without access to communication it is almost impossible to share personal narratives and experiences, vital for building social networks (Blum et al., 1991).

People with SSPI report a greater external locus of control (this is the extent to which an individual believes they are able to control what happens in their life) (Edyburn, 2006)

and depression (Wressle and Samuelsson, 2004). Those with the greatest level of communication impairment report the highest levels of depression (Edyburn, 2006). Depression and the locus of control in the general population are also known to be related to unemployment (Osberger et al., 1993).

Only 10% of people with SSPI are believed to be in employment in the United States of America (McNaughton et al., 2002a). While figures are not available for the level of employment in the United Kingdom, Eatson (1992) reported that those with SSPI are one of the least likely groups to be employed and those who are employed will earn significantly less on average than adults who are not disabled.

It has been suggested that access to employment would be easier if the communication impairment could be reduced or its impact lessened through assistive devices (McNaughton et al., 2002a).

Much work has been done into improving physical mobility, and both the mobility Assistive Technology research field and commercial market are large (Enders and Hall, 1990). By contrast, aids or communication is a small niche market. Given the effect of non access to communication can have on an individual it is an area worthy of attention.

2.3 Augmentative and Alternative Communication

Augmentative and Alternative Communication (AAC) is the general term for the methods used to aid communication by those for whom the usual form of communication through speech is not sufficient and is an area of practice which attempts to compensate for loss of verbal communication through a variety of techniques (Glennen and Descoste, 1997).

The aim of AAC is to provide access to communication for people with SSPI (ASHA, 2011).

Augmentative and Alternative Communication (AAC) can be categorised into aided and unaided communication (Glennen and Descoste, 1997).

2.3.1. Unaided AAC Communication

Unaided communication refers to methods of communication that do not rely on external devices. For those who have adequate motor control this could include Sign Language or Makaton. For people with SSPI whose motor control is not sufficient for this, there is the possibility of using facial or hand gestures (Millikin, 1997).

The advantage of unaided AAC is that it is portable and is always available to the user. However, use of unaided AAC is dependent upon the Communication Partner[2] understanding what the gestures or signs mean.

2.3.2. Aided AAC Communication

Aided AAC relies on an aid which is external to the user. This category of AAC can be divided up into low-tech and high-tech.

Figure 1 - Adult with SSPI Using Paper Word Board

[2] The term Communication Partner is used in this thesis to refer to the person who is communicating with the individual with SSPI.(Calculator, 1997)

Low Tech

Low-tech devices can be defined as "*anything that doesn't involve electricity*" (Scott, 1998 p. 13). Low-tech devices are not expensive to produce but are often difficult for a Communication Partner not familiar with this type of aid to understand. They are also not useful in attracting a Communication Partner's attention (Scott, 1998). An example of low tech AAC would be a paper word board (see Figure 1).

High Tech

High tech AAC devices use electricity and enable users to store and retrieve messages or compose messages using symbol sets or letters. High tech AAC will usually allow users to output their messages as synthesised voice (Glennen and Descoste, 1997).

Figure 2 - Selection of AAC Devices and Access Methods
(Taken from Misericordia University, 2008)

High-tech AAC aids (see Figure 2) are electronic devices that permit the storage and retrieval of messages, with most allowing the user to communicate with others using speech output (Glennen and Descoste, 1997). Modern high-tech AAC devices may also incorporate features such as: SMS text messaging, Internet browsing, E-Book readers, wheelchair controls, environmental controls and can even act as a remote control for televisions (Mayer-Johnson, 2010).

2.4 Abandonment Rate

Despite these exciting features in the devices, high tech AAC devices still have a high rate of abandonment (Johnson et al., 2006).

Previously little work has been done to investigate the level of abandonment of AAC, particularly in the United Kingdom (Holmes et al., 2010) but work is now underway to classify this figure. Various studies in other countries have put the average figure of abandonment of AAC devices at 30% (Johnson et al., 2006, Sutherland et al., 2005, Culp et al., 1986, Rory, 2009). The time between the first of these studies and the most recent would indicate that the abandonment rate of AAC has not altered significantly in the past 20 years. This means that almost one third of all devices prescribed and bought are not being used.

Each abandonment of a device represents wasted time and effort in training, a lost opportunity and a large amount of money spent (Johnson et al., 2006).

These figures relate to both high and low tech AAC devices but it is the abandonment of high tech AAC devices that causes the greatest disillusionment for users and professionals (Waller et al., 2005a) and given that they cost thousands of pounds (before even considering support costs) which must be met by the National Health Service (NHS)[3], local authority or charity (Kientz et al., 2006), there is good motivation to focus on the area of high tech AAC when investigating the issue of abandonment further.

[3] The National Health Service provides health care for all citizens of the United Kingdom based upon medical need as opposed to the ability to pay.

2.5 Reasons for Abandonment

There are many reasons for the abandonment of high tech AAC and not of all of these reasons are directly related to the device itself, e.g. negative family attitudes (Sutherland et al., 2005) or a lack of support for the end user (Johnson et al., 2006).

Other reasons are more closely related to the device itself and in particular the software that is running on the AAC device, e.g. the software is not flexible (Culp et al., 1986, Rackensperger et al., 2005, De Jonge and Rodger, 2006, Hoppestad, 2007) and cannot be used easily in different situations (Rackensperger et al., 2005).

It is through the software on the AAC device that the users can access communication (van de Sandt-Koenderman, 2004) and so it is vital that it works correctly for the device to be a success.

The study of the interaction between a user and software and how this interaction can be improved is known as Human Computer Interaction (HCI). HCI engineers can be seen as the bridge between the technical software engineers and the end users (Miesenberger et al., 2002). If the problems with the software are to be communicated effectively to the end software engineers they must be first understood by HCI experts.

It is proposed that by examining the reasons for abandonment in terms that apply to HCI it may become clearer to researchers in this field why the high tech AAC devices are not as successful as one would hope.

2.6 AAC Abandonment, Human Computer Interaction and Usability

Usability is a term used in HCI to describe how easily a piece of software can be used by its intended users to complete their intended tasks (ISO, 2010).

2.6.1. Means of Describing Software Usability

There are two main schools of thought when it comes to describing the usability of a piece of software (Sharp et al., 2007): Shneiderman's five usability measures and Nielsen's five usability components. Shneiderman's measures are: time to learn, speed of performance, rate of errors by users, retention of steps over time and subjective satisfaction (Shneiderman, 1998). Nielsen's components are: learnability, efficiency, memorability, errors and satisfaction (Nielsen, 1992).

Although these two different sets of components use different terms for the components they essentially are related to the same categories: how easy it is to learn to use the system, how quickly a user can carry out a specified task, how many errors the system generates and how easy it is to deal with these errors, how easy the system makes it for users to remember steps and the satisfaction the user gets from using the system.

Both of these categories are understood by HCI experts (Sharp et al., 2007). Nielsen's components were chosen in this thesis to categorise the reasons for abandonment of AAC which are related to the software, because according to Google Scholar, these components have been used more frequently in the literature than Shneiderman's measures (7363 times compared to 4663 times).

2.7 Categorisation of AAC Abandonment Using Usability Components

2.7.1. Learnability

Learning to use AAC devices can be a difficult and long process and a lack of training at this stage and throughout the life of a device has been cited as a reason for abandonment (Culp et al., 1986, Johnson et al., 2006, Light et al., 1996, Murphy et al., 1996). There is also the impact that long periods of training have on the friends and family of the AAC user which can contribute to abandonment (Parette and Angelo, 1996, Parette et al., 2000).

These reasons suggest that not only is there a lack of resources when it comes to providing training but that the training itself is too long. A shorter training period would mean that there was less of an impact on a family's daily routine. This shorter training period would also allow the trainers to work with more end users and would also allow more time for follow up training. This follow up training is very important; a user often needs time to test and experiment with their device in the user's home environment for problems to emerge (McNaughton and Bryen, 2007).

The best way to reduce the amount of training needed is to make the systems easier to learn (Grossman et al., 2009). A system which is designed to help users achieve tasks more quickly and without a great deal of prior training will not require such an extensive training period (Grossman et al., 2009).

2.7.2. Efficiency

Once a user has learnt how to use the system the next measure of usability is to look at how quickly they can perform the tasks, this is known as the efficiency measure (Nielsen, 1992).

One reason for abandonment is that the user prefers a simpler method of communication which is quicker for them (Johnson et al., 2006, Smith-Lewis and Ford, 1987). The end user may also be understood by some communication partners without an AAC device and they feel that the time taken on the device to communication is too long for the reward of being able to communicate with people who are not their usual communication partner (Johnson et al., 2006, Murphy et al., 1996). These reasons would suggest that the AAC device's benefits are not enough to outweigh the difficulties in using it. The devices are too slow to be useful for a user who has any other means of communicating.

The physical effort of using the device is cited by McCall (1997) as a reason for abandonment. While this does not relate directly to the device's efficiency it does relate to efficient uses of the end user's resources. A device should be designed to require as small an amount of a user's physical capability as possible, while still maintaining its own efficiency.

Parette (2000, 1996) in work done with families of AAC users gives a lack of time for family to help with AAC devices as one reason for abandonment. This means that the devices are taking too long to do tasks, and that devices should be designed with the time that may be available in mind. A device should allow tasks to be completed as quickly as possible to help families with busy schedules. This is linked to another reason for abandonment, that there is no time to program materials (Parette and Angelo, 1996). Again if this task was made simpler and quicker to perform the demand it makes on time would be reduced.

The other problem with efficiency that a user may face is the vocabulary not meeting their needs (Johnson et al., 2006). When the vocabulary is not available a user has the option of attempting to type the word or use gestures or vocalisation to help the communication partner guess what they want to say (Culp et al., 1986). Typing can be problematic for AAC users who may not have literacy skills (Millar and Kerr, 1998). Not having access to the appropriate vocabulary can slow or even stop communication. This means that users cannot complete their desired tasks on the device efficiently (Light et al., 1996).

2.7.3. Memorability

While it is important for a user to be able to learn to use the software quickly, it is also important that they are able to easily remember how to perform a task again the next time they use the system (Nielsen, 1992). Several papers (Johnson et al., 2006, McCall et al., 1997, Smith-Lewis and Ford, 1987) state that the system being too complex or

difficult is a reason for abandonment. A system that has many different components and steps to be completed in order to achieve a task will be difficult for users to remember (Norman, 2010). This is particularly important for users with SSPI who may also have cognitive impairments. This cognitive impairment could mean that a person with SSPI has problems with short term memory problems or problems in processing multiple tasks at once (Redmond and Johnston, 2001).

2.7.4. Errors

While it is almost impossible to ensure that any computer system will not generate an error (Daran and Thévenod-Fosse, 1996), it is important to ensure that when an error does occur that it is as quick and as simple as possible for the user to recover from it.

In AAC there are frequent references in literature on abandonment to the unreliability[4] of systems (Culp et al., 1986, Light et al., 1996, McCall et al., 1997, Murphy et al., 1996, Parette et al., 2000).

Many systems are unreliable and users of all forms of technology will be familiar with it occasionally breaking down (Parette et al., 1996). But the fact that it is being reported in the literature suggests that it is a large enough problem as to be a factor for the complete abandonment of an AAC device. This means that it is likely that the system does not make it easy for the end users to recover from errors and is too complex for errors to be corrected easily by the user and their communication partner.

2.7.5. Satisfaction

Satisfaction looks at how pleasant is it to use the system and if the user enjoys using the system (Nielsen, 1992). From an examination of the literature on AAC abandonment it

[4] Unreliability refers to a system that cannot be depended upon to act as expected without errors or system failure. (Sharp et al., 2007).

would seem this category can be subcategorised in four areas: customisation, environment, family and communication partners.

Customisation

Ratcliffe (1997) states that lack of customisation of devices is one reason for abandonment. AAC devices are designed for a large heterogeneous group, like many pieces of technology (Enders and Hall, 1990). Most mainstream software programs can now be customised to a user's particular needs or wishes (Dourish et al., 1999). AAC devices are difficult to customise. Without this customisation, a user's enjoyment of the device is likely to be reduced (Ratcliffe, et al., 1997).

Environment

AAC devices are designed in technology labs, but it is important to remember that they will be used in a user's own environment which itself may be varied in terms of temperature, light conditions, background noise and access to electricity (Newell and Gregor, 1999). A user's environment should also look at the people in the environment and what the accepted standard of behaviour is in the environment. Devices that do not fit into the environment or which do not give due consideration to the culture of the environment are more likely to be abandoned (McCall et al., 1997, Murphy et al., 1996, Parette et al., 2000, Parette and Angelo, 1996, Ratcliffe et al., 1997, Sigafoos and Iacono, 1993). If a device is not suited to what is going on then a user may struggle to use it or may feel embarrassed by using the device. Scherer's (2001) work in the USA has shown the importance of the environment being taken in account when matching people to all forms of technology, and especially assistive technology (Chandrashekar et al., 2006).

Family

Families are often consulted during the prescribing of AAC technology and even in some cases during the development of the devices. However as stated before, this designing will be done in a technology lab (Deruyter et al., 2007). Designers often do not consider how a device will fit into current family dynamics and the effect on a family's quality of life (Parette et al., 2000, Parette and Angelo, 1996). No matter how attractive a device looks if it doesn't make life better for the family as a whole it is likely to be abandoned (Parette & Angelo, 1996).

Communication Partners

The attitude of the communication partner and their motivation is crucial for a user's successful experience with an AAC device. A negative attitude from a communication partner (Light et al., 1996) or a lack of family support can result in abandonment (Culp et al., 1986, Johnson et al., 2006, Parette and Angelo, 1996). Some of these problems may be because of negative attitudes to AAC in general but many of them come from experiences of AAC being difficult to use (Johnson et al., 2006) and difficulties in communicating with people who use AAC (Johnson et al., 2006).

If the software on AAC devices was more usable then it is possible that communication between AAC users and communication partners could become more natural and therefore the communication partners would become more motivated to provide communication opportunities with the AAC user (Johnson et al., 2007).

2.8 Abandonment and Usability

It has been suggested in this chapter that AAC devices have an unacceptably high level of abandonment. As discussed in Section 2.6 many of the reasons for this abandonment can be related to poor usability. It would seem sensible therefore to investigate ways in which the usability of AAC devices can be improved.

In industry and academia it is accepted that while usability can be improved by following guidelines in design, the best way to improve the usability of software is when a developer involves the end users through a process known as User Centred Design[5] (Jokela et al., 2003).

Surveys have been conducted which show that the majority of HCI experts believe User Centred Design to be the best method of improving usability (Mao et al., 2005) and while there is little empirical evidence to prove its effectiveness, there are many cases where User Centred Design has not been conducted and the end software has failed due to poor usability (for a larger discussion see Chapter 3). In light of the lack of evidence to the contrary User Centred Design is currently accepted as the best means of improving software usability (Lazar et al., 2010).

The next stage of this research is to investigate the extent to which User Centred Design has already been conducted with this group of users.

2.9 Summary

This chapter has shown the effect on a person when they do not have access to communication. For those whose own means of communication are not sufficient AAC can offer the means of communicating. There are many different forms of AAC available, but the form that can perhaps offer the most potential is high technology AAC.

There is a rejection rate of almost 30% of AAC devices; this means that all the effort that is required on the part of the end user, their family and their speech therapy team to select and become familiar with the device is wasted.

[5] User Centred Design is a process for the continual involvement of end users throughout the development of a product. It is discussed in-depth in Chapter Three.

There is good motivation to investigate the extent to which User Centred Design has already been conducted with participants with Severe Speech and Physical Impairments, however before this can be carried out, Chapter Three will provide an overview of the User Centred Design lifecycle.

Chapter 3. **User Centred Design**

"*Talk to the organ grinder, not the monkey*"

Robert, a participant in the study with SSPI

3.1 Introduction

As discussed in Chapter Two the usability of the software on high tech Augmentative and Alternative Communication (AAC) devices is poor. The best way recognised by industry and academia to improve usability is by conducting User Centred Design (Vredenburg et al., 2002). This chapter takes a step away from AAC to provide a short overview of the User Centred Design process, before returning to examine the issue of User Centred Design in the development of AAC in Chapter Four.

This chapter concludes with a short example of the problems that can occur in general software development when User Centred Design is not followed.

3.2 User Centred design

User Centre Design has its origins in Gould and Lewis's 1983 paper which first put forward the three principles of design needed to create software that is easy to use (Brown-Sica, 2010). These principles were: early and continual focus on users; empirical measures using simulations; and prototypes and iterative designs (Gould and Lewis, 1983). These principles are found throughout the process that is now known as User Centred Design, but when they were first proposed in the 1980s they were not accepted by most designers (Gregor et al., 2002). Gould and Lewis continued to pursue the idea of focus on users during design and over time it gradually became more accepted. By 1999 it was given its own standard by the

International Standards Organisation (1999). It is now considered the best way to improve the usability of software, above guidelines and design frameworks (Vredenburg et al., 2002).

3.3 International Standards in User Centred Design

ISO 13407:1999 (known commonly as ISO 13407) built on Gould and Lewis's principles of design (1983) to put forward four updated principles of design: the active involvement of users, an appropriate allocation of function between users and technology, iterations of solutions and multi-disciplinary design teams (ISO, 1999). There are four stages of software development: understand and specify the context of use, specify the user and organisational requirements, produce design solutions and evaluate design against requirements (ISO, 1999). The new standard for User Centred Design is ISO 9241-210 (2010) which has replaced ISO 13407. The new ISO takes the existing recommendations and provides more detail on them. Many of the recommendations from ISO 13407 are now essential criteria which must be fulfilled for a product/process to be classed as User Centred Design (ISO, 2010).

In ISO 13407 (1999) the User Centred Design process was seen as a separate process, which could run concurrently with the actual software development. ISO 9241-210 gives a process which is to be incorporated into the whole software development, not as a process on its own (ISO, 2010). The design of a piece of software should be driven and defined by the users' feedback (ISO, 2010).

Unlike ISO 13407 (1999) when iteration was a suggestion concentrated in the evaluation phase, it is now a requirement and should be carried out in every phase of the process (ISO, 2010). The differences between the two ISO processes can be seen in Figure 3.

The four processes from ISO 13407 (1999) remain in the new standard: identify the context of use, gathering requirements, producing design solutions and evaluating the solution against requirements (ISO, 2010) but are now iterated. This means that the software will be developed through several lifecycles, and the end users taking part in the development will have a greater impact on the end result as their requirements and ideas for design are being continually returned to (ISO, 2010).

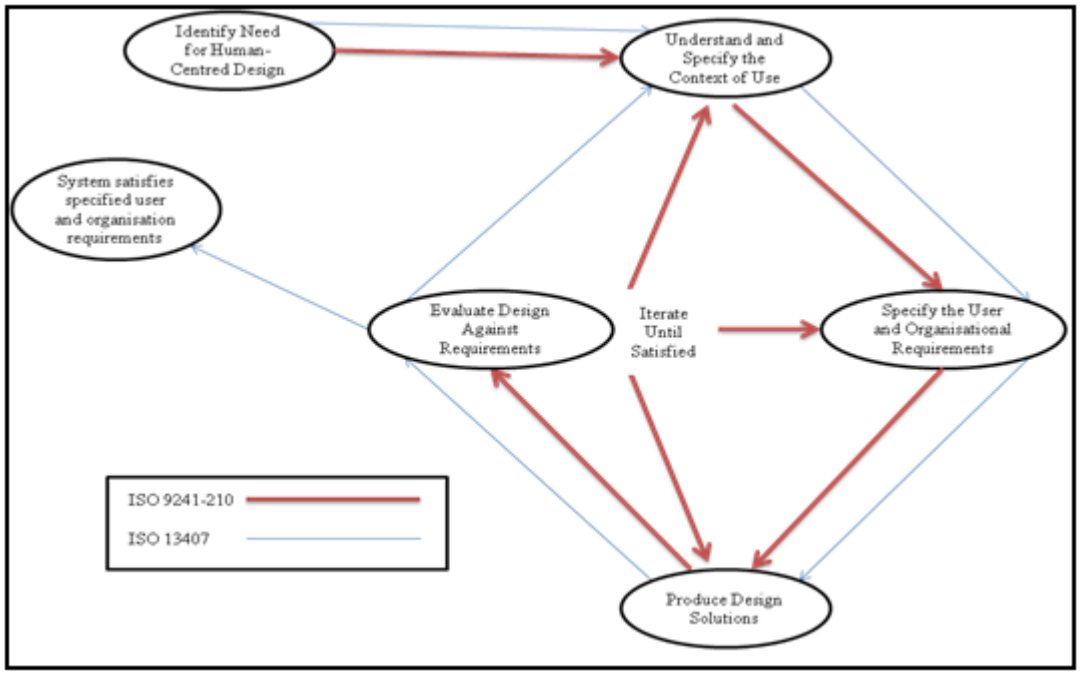


Figure 3 – Comparison of ISO 13407 and ISO 9241
(Adapted from ISO, 1999 p. 6, ISO, 2010 p. 10)

3.3.1. Determining the context of use

The context of use looks at who will be using the software, the environment it will be used and what the motivation for using it is (Maguire, 2001). By the end of this section the development team must be able to provide details on the different stakeholders in the product, including the end users and their goals, the tasks the system should support and the environment in which the software will be used (ISO, 2010). Even at this early stage, the users should be involved in helping to provide the

information which is used to inform the requirements and should be referred back to in forming the requirements (Lazar et al., 2010).

3.3.2. Requirements

The needs of the users and stakeholders have to be gathered while considering the context of use. The requirements should be focussing on what the users want to achieve and not how the system will support this (ISO, 2010). The requirements should also include how any constraints (e.g. "the software will be used outside") imposed by the context of use will be addressed. When there are conflicts or potential conflicts between requirements these should be resolved at this stage (ISO, 2010). How these conflicts are resolved (e.g. rationales, factors and weightings used in tradeoffs) should be noted so that they can be referred back to later in development or when an update is being created (Boehm and In, 1996)

3.3.3. Design

When conducting User Centred Design one of the major goals for the software should be to provide a good user experience. A good user experience is one where the user finds the software easy to use and enjoys using the software (Bach et al., 2009). One of the areas which has a major impact on the user experience is the design of the product (Redmond and Johnston, 2001).

There are various information sources which should be considered and used when developing design solutions. These information sources include the context of use, baseline evaluations, what is currently happening in the field, guidelines available and the research team's own experience (Jeffries et al., 1981). The users should be involved in the design process or shown the proposed solutions as this may encourage further requirements. As the process progresses the designs should become more concrete (e.g. using scenarios, simulations and mock ups) (ISO, 2010).

The interaction between the users and the systems is a crucial feature of the design process and developers should give careful consideration as to how the user will interact and not just what they will do as a result of the interaction (Patton, 2002). The new ISO takes the principle of user/researcher interaction in design further saying that it "should" be done, rather than saying it is "best" if it is done (ISO, 2010).

3.3.4. Evaluation

The evaluation of software in User Centred design is now a required activity (ISO 13407 stated that it is essential) (ISO, 1999, ISO, 2010). Evaluation should take place throughout the development process, even at the beginning when design concepts can be evaluated to better understand user's needs (ISO, 2010). The two main approaches in User Centred evaluation are user-based testing and inspection based evaluation (Redmond and Johnston, 2001).

In user-based evaluation when prototypes are used the user should be asked to carry out tasks rather than simply be shown the prototypes (ISO, 2010). The user will then report on their thoughts about the software and any problems they encountered, quantitative objective measures may be taken as well such as time taken to complete a task, or errors made (Boehm et al., 1976).

When inspection based evaluation takes place, experts use usability and accessibility guidelines or requirements to evaluate the prototype. There are a variety of guidelines available, some provide strict criteria which the software should meet, (e.g. the International Standards Office ISO/TS, 2003) while others provide more general guidance on important aspects of the software. This more general guidance is available from a variety of sources including usability websites and papers on

usability (e.g. Bevan and Spinhof, 2007). Heuristic evaluations provide a means of inspection based evaluation. Nielsen and Molich (1990) specify eleven heuristics which software should be evaluated against (e.g. is there a match between the system and the real world).

The software will also be checked against the requirements given by users in the earlier stages of the software lifecycle to ensure it meets all of them (Sreemani and Atlee, 1996). Inspection based evaluations should not be the sole method of evaluation but can be used to eliminate major issues before user testing. In User Centred design there should be long term monitoring of the product (Woods et al., 1996).

To achieve conformance with ISO 9241:210 a process must meet all of the applicable requirements and detail why any recommendations or requirements have not been followed (ISO, 2010).

3.4 Example of Problems when User Centred Design is not conducted

There are numerous examples of the problems that can occur when user centred design has not been done in the general Software Development field. One extreme case of this is the Therac-25 case. The Therac-25 was a machine designed to provide radiotherapy to cancer patients. Eleven Therac-25 machines were installed in Northern America in the 1980s (Taylor et al., 1983) and six accidents are known to have occurred in which large overdoes of radiation were accidentally administered to patients between 1985 and 1987 following a software update (Leveson and Turner, 1993).

The cause of this problem was not due to a fault in the software operation, instead it was due to an error on the user interface. The developers had attempted to simplify the user interface which had originally required the end user to input the all the settings through a computer terminal and a control panel (Edmond and William, 2004). The developers felt this was redundant and changed the software so that the settings only had to be entered by hitting the return key and then confirmed on the terminal by again hitting the return key. Little user input had been sought during the development and evaluation of the system, thus developers did not have a full understanding of how the user would operate the system.

When the system was deployed "live" the users began to hit the return key on the confirmation screen as a matter of habit, similar to a double clock on the mouse. This meant that on the six occasions detailed in the Therac-25 case report, crucial overdoses were not noticed on the confirmation screen. A review of the software in 2003 suggested that had the end users been consulted regularly from the beginning of the development process as opposed to only once the system was complete, this fatal flaw could have been avoided (Leveson and Turner, 1993).

3.5 Summary

This chapter has discussed the history of User Centred Design and the different stages in each process. An example has been provided of the problems that can occur when User Centred Design is not followed.

The methods that can be carried out in each stage of the User Centred Design process are discussed in Chapter Five.

Now that the process of User Centred Design has been discussed it is possible to look at how much work is currently happening in User Centred Design in AAC and to carry out a systematic literature review on the ways in which User Centred Design has been conducted with adults with SSPI.

Chapter 4. Literature Review on User Centred Design and Adults with SSPI

"Sometimes people talk to you but they don't seem to take it in, they can hear you but they don't seem to listen"

Pam, a participant in the study with SSPI

4.1 Introduction

This chapter discusses the involvement of end users in Augmentative and Alternative Communication (AAC) software development and then provides a systematic literature review on how adults with Severe Speech and Physical Impairments (SSPI) have been involved in User Centred Design.

Before the review is introduced, a short overview of the use of Systematic Reviews in software engineering is provided.

This chapter concludes by evaluating the extent to which User Centred Design has been conducted with people with SSPI and discusses the rationale behind the research question.

4.2 Current Amount of User Centred Design in Development of Assistive Technology

The first examination of the literature was to see how much User Centred Design was currently being integrated into the development of AAC and how this compared to development of other assistive technologies. Assistive Technology conferences and journals such as RESNA and sister conferences have a focus on rehabilitation engineering as a whole and do not have a focus on software engineering (RESNA, 2011). While clinical organisations such as ISAAC (Larraz and Escoin (eds), 2010)

have a focus on AAC they again do not focus on software engineering. It was therefore concluded that a review of ACM ASSETS would provide a representative sample of current research projects focusing on Assistive Technology within a software engineering context. A review of the conference proceedings from the years 2006-2010 shows that on average 15% of papers on development of technology employed User Centred Design (see Figure 4). The papers from the conference proceedings were first examined by reading the abstracts, where it became clear during the abstract that the paper employed User Centred Design (e.g. mentioned using methods with end users in the abstract) or clearly did not employ User Centred Design (e.g. was a purely technical paper), these were included in the total and not examined further. Papers which were not clearly in either category from the abstract were read in full. The author examined the papers for description of how development had taken place and who the participants (if any) had been in the development of the software.

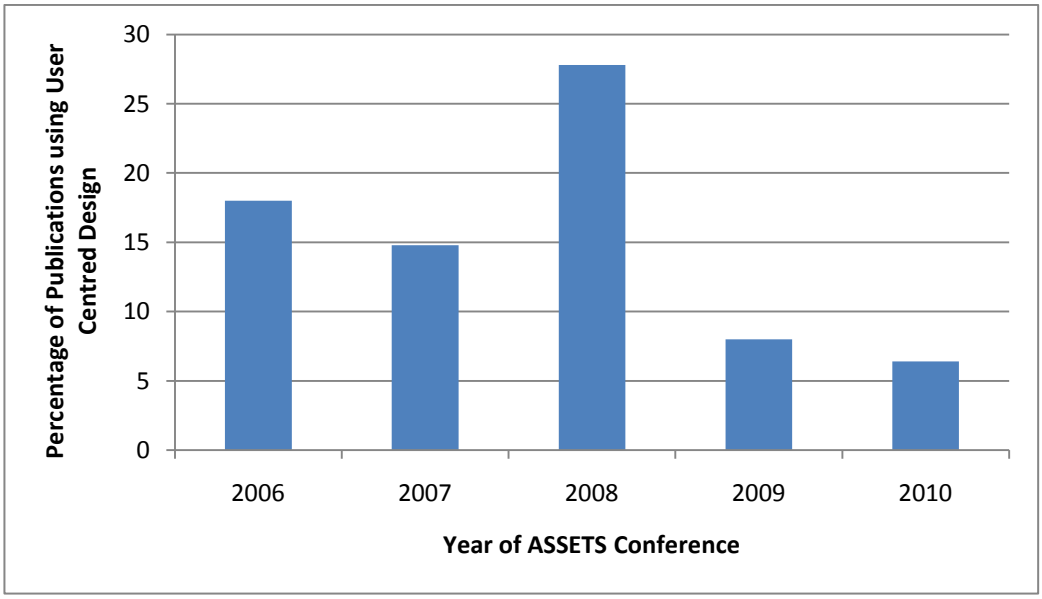


Figure 4 - Use of User Centred Design in ASSETS Proceedings Publications

While this figure is still low compared to general technology development (a review of ACM CHI (SIGCHI, 2010) the premier conference in Human Computer Interaction had 34% of papers involving User Centred Design) the figure is higher than for AAC

development. A review of papers in ASSETS shows that no papers which dealt with AAC development used User Centred Design[6].

Due to this, an investigation was conducted into what work has been done in User Centred Design in AAC development, what methods were used and what alternatives to user involvement were used in different stages.

4.3 Rationale for a Systematic Review

There was little empirical evidence within the existing literature regarding the current state of User Centred Design and participants with Severe Speech and Physical Impairments (SSPI).

It was therefore necessary for the author to conduct a review in this area which looked at publications which had involved adults with SSPI at some stage in development of technology.

As this was a multi-disciplinary area it was important to analyse the literature from different areas consistently. In other areas of research, particularly clinical research, when multi-disciplinary literature or large volumes of literature are being reviewed, the Systematic Literature Review process have been found to be invaluable (Mulrow, 1994).

4.3.1. Systematic Review Process

Systematic reviews have a strict process to follow before one can be carried out and it is important to have a full understanding of the ten stages to this process (Mulrow, 1994). Systematic reviews begin by developing a research question (Stage One) and then by creating a review protocol (Stage Two) (Brereton et al., 2007). This review protocol specifies what electronic databases will be searched for literature, how the databases

[6] A summary of the main reasons given by papers at ASSETS and other studies for not using User Centred Design in AAC development is provided in Section 4.5.

will be searched and how the retrieved literature will be analysed for inclusion in the review (Glanville, 2006). This review protocol should then be validated by an independent researcher (Stage Three) (Glanville, 2006). Search strings are then developed and entered into the specified online electronic databases of literature (Stage Four) (Mulrow, 1994). Once these publications are retrieved, the abstracts are first analysed to check they meet the inclusion criteria specified in the protocol before full publications are retrieved and analysed (Stage Five) (Mulrow, 1994). The remaining publications are assessed for quality and given different weightings based on this quality (Stage Six) (Glanville, 2006). It is not until Stage Seven that the data is extracted from the retrieved publications, and synthesised in Stage Eight into a form that is suitable for answering the review question(s) (Glanville, 2006). The report on the findings is then written (Stage Nine) and validated (Stage Ten) (Mulrow, 1994).

Systematic reviews are now being used in new areas, and one of these areas is software engineering (Brereton et al., 2007). The benefits that Systematic Reviews bring strongly appealed to many software engineering researchers, however very quickly it was discovered that the well tried and tested protocol for use in clinical research did not translate fully into software engineering (Brereton et al., 2007).

The main areas which are not directly translatable are sections four, five and six. Brereton et al., (2007) discuss these difficulties and offer suggestions for how these problems can be overcome:

- Stage Four – Identify Relevant Research

  In systematic reviews in clinical research, search strings would be created and used in electronic literature databases, all of these databases are organised in a similar way and one search string will work in all of these databases (Brereton et

al., 2007). In software engineering the main electronic databases[7] are not all compatible in this way. Different search strategies will be needed for individual databases (Brereton et al., 2007)

- Stage Five – Select Primary Studies

  In clinical research, the abstracts of the publications retrieved from the databases would be assessed to establish if it meets the criteria specified in the protocol, full publications of abstracts passing this stage would then be used to confirm that the study meets the criteria. In software engineering abstracts are often too poor to rely on when selecting studies and often the full publication, or at the very least the conclusion will need to be read as well (Brereton et al., 2007).

- Stage Six

  Stage six involves assessing the quality of the studies included in the review. This often means ensuring that there is a limitation of bias in the study and that there has been both internal and external validation of the results (Brereton et al., 2007). Studies are given a weighting based on their quality and this is used when investigating the contribution the study makes to the overall results of the review. In software engineering this stage is often not required or even possible; it depends on the type of empirical study included in the review and what information the researcher is wishing to gain from the studies (Brereton et al., 2007).

Despite these significant modifications Brereton's study (2007), which involved three systematic reviews in software engineering, showed that systematic literature reviews

[7] The main electronic databases in Software Engineering are: IEEExplore, ACM Digital Library, Google Scholar, Citeseer library, Keele University's electronic database, Inspec, and ScienceDirect (Breeton et al., 2007)

do have benefits for the field in guiding literature searches and assisting researchers who wish to gather statistical evidence on reviews.

An example of the increasing awareness of systematic reviewing in software engineering is that, since its publication in 2007, eighty-nine studies have cited Brereton's study (2007). Of these eighty-nine, seventy-seven of the studies were systematic reviews. Systematic reviews have been particularly beneficial when reviewing large areas of data from primary studies (Bailey et al., 2007) or multi-disciplinary fields (Armitage et al., 2009).

Taking this into account, the author made the decision that, due to the multidisciplinary nature of this research, it would be useful to conduct a Systematic Literature Review in answering the question of "How have studies involved adults with SSPI in User Centred Design?".

4.4 User Centred Design Literature Review

4.4.1. Rationale

There is little information in the existing literature as to the extent to which User Centred Design has been conducted with participants with SSPI in the development of software. It has been stated that this is an under researched area (Waller et al., 2005a), but no studies have investigated what the extent of this is. This review aims to answer the research question of "How have end users with SSPI been involved in the User Centred Design of software and at what stages of the process was this involvement?"

4.4.2. Method

A systematic approach was taken to searching the electronic databases, the six databases searched were: The ACM Digital Library, IEEExplore, INSPEC, hcibib, Web of Science and ScienceDirect. This search did not include medical databases (except for Web of Science and ScienceDirect which cover medicine as well as engineering and

science research), the aim of the review was to investigate User Centred Design from the perspective of software engineering and it was felt that the majority, if not all, of these papers would be found within these databases (Brereton et al., 2007).

The ACM Digital Library does not support search strings and so keyword combinations were searched for individually. The other databases were searched using search strings using thesaurus terms of User Centred Design and Communication Impairment. Examples of the search strings are detailed in Appendix G. Following this an author search on recovered studies was conducted.

Inclusion criteria for this structure review were (a) published in a peer reviewed journal or conference; (b) published in English; (c) discussed the inclusion of participants with SSPI in the software development process; and (d) were empirical studies. Excluded from the review were articles which stated a product was designed as a result of user centred design but did not elaborate on this.

There are difficulties in establishing study quality in software engineering (Brereton et al., 2007) and so for this review the quality appraisal was embedded within the inclusion rules (in criteria a). All of the studies in this review had been peer reviewed; this was deemed sufficient in this instance. No time limits were applied to studies, the author was interested in all studies which had included participants with SSPI in User Centred Design and as such, did not feel a time limit was appropriate. The databases themselves covered the years 1872 (IEEExplore) to the present date.

A total of twenty-three studies were recovered, of which eight did not meet the inclusion criteria (Barreto et al., 1999, Clayton, 2006, Foreman and Crews, 1998, Small et al., 2005, Lundalv et al., 1998, Lundalv et al., 1999, Newell and Gregor, 2000, Panek et al., 1999). The criteria upon which each of these studies are excluded is given in Table 1.

Table 1 - Reasons for Exclusion

Paper	**Inclusion Rule A** ***published in a peer reviewed journal or conference***	**Inclusion Rule B** ***published in English***	**Inclusion Rule C** ***discussed the inclusion of participants with SSPI in the software development process***	**Inclusion Rule D** ***were empirical studies***
(Barreto et al., 1999)	Passed	Passed	Failed – Discussed people with physical impairment only	Passed
(Clayton, 2006)	Passed	Passed	Failed – no User Centred Design discussed	Failed - commentary piece
(Foreman and Crews, 1998)	Passed	Passed	Failed – no User Centred Design discussed	Passed
(Small et al., 2005)	Passed	Passed	Failed – no User Centred Design discussed	Passed
(Lundalv et al., 1998)	Passed	Passed	Failed – no User Centred Design in software. The description of participants does not make it clear if they had SSPI	Passed
(Lundalv et al., 1999)	Failed – Conference is not peer reviewed	Passed	Failed no User Centred Design	Passed
(Newell & Gregor, 2000)	Passed	Passed	Failed – no discussion of User Centred Design	Failed – commentary paper
(Panek et al., 1999)	Failed – Conference is not peer reviewed	Passed	Failed – no discussion of User Centred Design	Passed

The fifteen studies which met the criteria for inclusion were examined for themes relating to the four stages of user centred design as described by ISO 9241-210 (ISO, 2010): understand and specify the context of use, specify the user and organisational requirements, produce design solutions and evaluate designs against requirements (See Chapter Three). A full description of the studies is provided in Appendix H. These four stages create the User Centred Design process but are clearly separated with their own

outcomes, and by analysing the results in this fashion it was possible to see which areas of the process are currently neglected in the development with participants with SSPI.

4.4.3. Examination of Results

The results are categorised by the four phases of the User Centred Design lifecycle (see Chapter Three). These results are summarised in Table 2.

Understand and Specify the Context of Use

Understanding and Specifying the Context of Use involves gaining knowledge of the users, their characteristics, other stakeholders (e.g. assistants, families) and the environment the software will be used in. The developers should also understand the user's goals and tasks by the end of this stage (ISO, 2010).

All of the studies found in this literature review employed some technique to understand and specify the context of use. In this review seven of the studies used only a literature review of existing software and/or work done in the field (Visser et al., 2008, Allen et al., 2007, McCoy et al., 1997, Dunlop et al., 2002, Steriadis and Constantinou, 2003, Allen, 2005, Hornof, 2008, Waller et al., 2009). The two studies which did not use a literature review as part of their understanding and specifying the context of use, used observations of the users and how they currently performed tasks (Davies et al., 2004, O'Connor et al., 2006).

Other methods were used in addition to a literature review in seven of the studies such as a discussion with experts on the issues (Light and Drager, 2007, Boyd-Graber et al., 2006, Hengeveld et al., 2008a).

Only one publication worked with end users and interviewed them on where and how they would like to use the new technology (Davies et al., 2004).

Table 2 - Methods Used in Stages of User Centred Design Process

Paper	Understand and Specify Context of Use	Specify the user and organisational requirements	Produce Design Solutions	Evaluate Design Against User Requirements
(Waller, et al., 2009)	Conducted Literature Review	Expert Discussion	Life Like Proxy Users	End Users Longitudinal
(Dunlop, et al., 2002)	Lit Review	____	Life Like End Users	End Users Short Term
(O'Connor, et al., 2006)	Distance observation of End User	Prototypes with End Users	Lo fidelity End Users	End Users Short Term
(Steriadis & Constantinou, 2003)	Conducted Literature Review	____	____	End Users Longitudinal
(McGrenere et al., 2003)	Conducted Literature Review	Interviews with end users	Range Lo-Hi fidelity End Users	____
(Tee et al., 2005)	Conducted Literature Review	Examine existing systems	High Fidelity End and Proxy users	End Users Short Term
(Allen, et al., 2007)	Conducted Literature Review	Participatory Design with experts	High Fidelity End Users	End Users Short Term
(Visser, et al., 2008)	Conducted Literature Review	____	Lo Fidelity Proxy Users	____
(Light, Page, Curran, & Pitkin, 2007)	Conducted Literature Review Expert Users Discussions	____	Lo fidelity Proxy Users	____
(Boyd-Graber et al., 2006)	Conducted Literature Review Expert Users Discussions	Participatory Design with experts	Range Lo-Hi fidelity Proxy users	End users longitudinal
(Allen, 2005)	Conducted Literature Review	-Experts Discussion -Prototypes with End Users -Interview End Users -Examine Existing Systems -Participatory Design with Experts	Range Lo-Hi fidelity End Users	____
(McCoy, et al., 1997)	____	____	Lo fidelity End Users	____
(Hornof, 2008)	Conducted Literature Review	____	____	____
(Davies, et al., 2004)	-Observation of users -Interviews	Multiple Prototypes with end users	____	____
(Hengeveld, Voort, Hummels, Overbeeke, et al., 2008)	Expert Users Discussion Conducted Literature Review	____	Range Lo-Hi Fidelity with end users	____

4.4.4. Specify the User and Organisational Requirements

The requirements section of software development was not detailed in all of the studies in this review; eight of the studies did not provide details on how the requirements were gathered (Dunlop et al., 2002, Steriadis and Constantinou, 2003, Davies et al., 2004, Light and Drager, 2007, Hengeveld et al., 2008a, Hornof, 2008, Visser et al., 2008). Methods employed in gathering requirements included holding discussions with experts

(Allen, 2005, Waller et al., 2009) and conducting participatory design with proxy users[8]. (Allen, 2005, Boyd-Graber et al., 2006, Allen et al., 2007). Tee et al., (2005) and McCoy et al., (1997) used examination of existing systems as their only method in requirements gathering while Allen (2005) used it in addition to other methods. The involvement of end users at this stage was conducted in four studies in the requirements gathering (Davies et al., 2004, Allen, 2005, O'Connor et al., 2006, McGrenere et al., 2003). Multiple prototypes were provided for the end users in order for them to judge and provide additional requirements in three of these studies (Davies et al., 2004, Allen, 2005, O'Connor et al., 2006) and two studies used interviews with the end users (McGrenere et al., 2003, Allen, 2005).

4.4.5. Produce Design Solutions

There were no details on the design solutions for two of the studies (Steriadis and Constantinou, 2003, Hornof, 2008). The remaining fourteen studies were split between using end user participants and using proxy participants. They also varied in whether they used low or high prototypes. High level prototypes with proxy users were used in three studies (Tee et al., 2005, Hengeveld et al., 2008a, Waller et al., 2009). Tee et al (2005) also used end users with high level prototypes as did Dunlop (2002), Davies (2004) and Allen (2007)**.** Only low level prototypes were discussed in four studies, two showed these designs to the end users (McCoy et al., 1997, O'Connor et al., 2006) with

[8] Proxy User is a term for the use of a participant who is not an end user but who simulates being an end user when the researchers do not believe it is possible to use the actual end user (Ibrahim et al., 2007)

the remaining two showing the low level prototypes to proxy users (Light et al., 2007, Visser et al., 2008). Boyd-Graber et al (2006) discussed the involvement of proxy participants at all stages of the process.

4.4.6. Evaluate Designs against User Requirements

There were eight studies which discussed the methods by which the system was evaluated. All of these studies used the end users to evaluate the system, either in a short term study (Dunlop et al., 2002, Tee et al., 2005, O'Connor et al., 2006, Allen et al., 2007, Hengeveld et al., 2008a) or in a longitudinal study (Waller et al., 2009, Steriadis and Constantinou, 2003, Boyd-Graber et al., 2006). Of those studies which did not include details of the evaluations, six were still in development and had not reached the evaluation stage yet (McCoy et al., 1997, McGrenere et al., 2003, Davies et al., 2004, Allen, 2005, Hengeveld et al., 2008a, Hornof, 2008). The remaining two studies were only looking at a particular aspect of software design (Light et al., 2007, Visser et al., 2008).

4.4.7. Discussion

No publication in this review included direct interaction with participants in all four stages of the user centred design process as defined by ISO 9241-210 (ISO, 2010).

None of the studies included end users actively in the understanding and specifying the context of use, although three used experts in the field in discussion (Boyd-Graber et al., 2006, Light et al., 2007, Hengeveld et al., 2008a). O'Connor did not directly interact with the end users at this stage and instead used indirect observation of the end users (O'Connor et al., 2006).

Innovative methods were used to gather requirements from end users in four studies in this review (Davies et al., 2004, Allen, 2005, Allen et al., 2007, O'Connor et al., 2006).These methods included presenting participants with a variety of prototypes in order to spark discussion on what the user would and would not like to see in the final

system. While this is not the first time these methods have been used for requirements gathering, it is a change from traditional focus groups and interviews. Expert opinions were relied on in three studies (Boyd-Graber et al., 2006, Allen et al., 2007, Waller et al., 2009), although Allen (2007) also worked with end users.

The fourth step in ISO 9241-210 is the evaluation of the solution against user requirements. Within this literature review it is difficult to examine how successful this evaluation is as so few of the studies took the requirements (on which evaluations are measured against) directly from the end users. Only eight of the studies reported on the evaluations, all of these did include end users in the evaluation either in a longitudinal or short term study. It is perhaps not surprising that all of the evaluations reported were able to use end users as evaluators, as these will be people using the system once it is finished. Some considerations might need to be taken into account when planning evaluations with these users such as whether traditional evaluation techniques are appropriate with this user group. A citation search and an author search was conducted following this literature review to investigate if any papers had been published which detailed evaluations for the papers which did not report on evaluations. However, no papers were found.

It can be seen from the literature review that there has been limited work done in User Centred Design with people with SSPI, and what work has been done has been limited and has not encompassed the entire software development process.

4.5 Problems Cited in Conducting User Centred Design with Participants with SSPI

Studies on the topic of involving end users with complex disabilities, in particular those with SSPI, in User Centred Design have discussed the problems that can occur when attempting this.

4.5.1. Representative Sample

When conducting User Centred Design the participants are likely to only be a small sample of the entire user group; it is therefore important to make sure that the sample is representative of the user group. For example, if the software was being designed for use in a school one would expect that the participants would include teachers and pupils with a range of ages and a mixture of both genders (Preece, 1993).

No two people with SSPI will have an identical set of impairments or needs, and there is a great variety of user characteristics, so there are problems in finding representative users (Glennen and Descoste, 1997).

One important task in User Centred Design is to specify the characteristics of the user group and their abilities and needs. This variation of impairments and characteristics of the population with SSPI can make the task of specifying the characteristics of the user group difficult (Newell and Gregor, 2000).

4.5.2. Achieving Consensus

While ensuring that a purposive sample of participants are involved is one way to improve the validity of decisions, another challenge to achieve agreement between all the participants on a decision (Boehm and In, 1996). One risk when working with adults with SSPI is that those participants who are most adept at using their AAC device will be able to provide the most information on their preferences and requirements. This means there can be a tendency to pay too much attention to "*the articulated needs of one user*" (Newell and Gregor, 2000 p. 41).

4.5.3. Communicating Thoughts

There can be the risk of paying the most attention to participants who can communicate the most effectively, but even with these participants it can be very challenging to hold a conversation with them which goes into more detail than simple phrases, and delves into opinions and feelings (Black et al., 2010a). It is important particularly when

gathering requirements or conducting design that the participants can provide good feedback and explain why they hold an opinion (Lazar et al., 2010).

Newell suggests that participants may struggle to communicate their thoughts (Newell and Gregor, 2000). The author understood this concern to mean that a participant may not be able to offer suggestions for how features of a design or discuss their views on the way a design is progressing.

4.5.4. New Technology

Enabling participants to communicate their thoughts can be especially challenging when creating new technology (Carmichael et al., 2005). AAC research is frequently at the forefront of technology and often focuses on technology that has not previously been envisaged (O'Keefe et al., 2007). Careful consideration must be given to methods centring around new technology to ensure that they are suitable and ethical for use with adults with SSPI.

4.5.5. Ethical Methods

There are a wide variety of methods used in the development of software (see Chapter Five); however when working with participants with SSPI, some of the traditional methods used to uncover thoughts may be unethical (Braun et al., 2010).

For example, one of the traditional methods for evaluating the usability of software is to watch a participant attempt to use it and monitor the mistakes they made. It could be deemed unethical to do this with a user with SSPI as they may not fully understand and become distressed when feeling that they are making mistakes (Newell and Gregor, 2000).

Another issue is that often one of the measures of success is the level of disappointment shown by participants when the software is taken away (Newell and Gregor, 2000),

again this may cause undue distress to participants with SSPI, particularly if the software has improved their ability to communicate.

4.5.6. Legal Issues

Another ethical issue to consider in User Centred Design is how informed consent can be given by participants. One reason often given by researchers for not working with adults with SSPI and using proxy participants instead, is a difficulty in gaining informed consent (Braun et al., 2010). Many developers believe that participants with SSPI could be deemed legally 'incompetent' and this would mean they are unable to take informed consent (Newell and Gregor, 2000). It may also be difficult for a researcher to be sure that they are obtaining full informed consent.

An additional legal issue is that often in research, participants are recruited with the offer of payment, however payment may conflict with rules on benefit payments (Newell and Gregor, 2000).

Research projects frequently offer participants remuneration in some form in return for their assistance in their work. This appeals to students who will volunteer regularly and ensures a researcher can have enough participants to carry out their work. This can cause problems when working with adults with SSPI as it may interfere with benefits rules (Newell and Gregor, 2000). Some participants with SSPI may be employed and not receiving incapacity benefit, but will probably still receive some form of benefit for assistance or care support, any additional significant payment may affect how this is calculated. For the majority of adults with SSPI who do not work any form of payment can affect their benefits. Their benefits package is likely to be complicated and encompassing many different forms of benefits. It can detrimental to a participants financial situation to receive money (Newell and Gregor, 2000).

4.5.7. Purchase of Product

As participants with SSPI frequently rely upon benefits, they are unlikely to have much, if any, disposable income (Enders and Hall, 1990). The end user is the participant in the research but is often not the end purchaser (Newell and Gregor, 2000). This alters the usual business model. In a traditional technology route to market the product will be built around the market (that is the end user) problem and the channel (that is the way it is sold) will be designed in the way that the market wants to buy (Quesenbery, 2000).

There are examples however of other projects which have included people with other disabilities in user centred design (Ma et al., 2007, Adamo-Villani, 2006, Matthews et al., 2005, Petrie et al., 2006). Guidelines have been created for those wishing to develop technology for people with disabilities in general (ISO/TS, 2003, ISO, 2008) but these guidelines focus more on the technical specifications rather than usability.

At present there are no projects which include adults with SSPI in all stages of the User Centred Design software development process which could act as an example to software developers wishing to conduct similar work, nor are there any guidelines available on how to conduct user centred design with participants with SSPI.

4.6 User Centred Design and SSPI

The literature review has shown that to date limited work has been conducted in User Centred Design with adults with SSPI in the development of software. Before researchers can investigate if end user involvement in the design process reduces the abandonment of AAC devices, first an investigation into the feasibility of adults with SSPI being involved in User Centred Design must be carried out.

While it is important to include a wide variety of stakeholders in the development of assistive technology, the contribution that the end users themselves also bring cannot be overstated (Vredenburg et al., 2002). The end users cannot be expected to design a

system entirely on their own, but their views and opinions should be valued and taken into account throughout the design process (Olsson, 2004).

The remainder of this thesis concentrates on the involvement of the end users in the User Centred Design of assistive technology, while it is anticipated that in a full industrial project a variety of stakeholders would be involved, for the purpose of this work the intention was to establish if the end users could be involved fully.

4.7 The Research Question

The literature shows that communication is vital for humans and that for those who cannot communicate verbally AAC devices have the potential to greatly improve the quality of their lives (Glennen and Descoste, 1997, Beukelman and Mirenda, 1992). In Chapter Two it was shown that at present this potential is not being realised and that many AAC devices are being abandoned. In other areas of software development it is accepted that when end users are involved as co-designers through User Centred Design the usability of technology increases. Currently little work has been done in User Centred Design with participants with SSPI and investigation into what difference this makes to the usability of devices is required.

The literature cites several problems with involving participants with SSPI in User Centred Design and at present it is not possible to establish the difference that conducting User Centred Design in development makes to the usability of software for people with SSPI. Before this investigation can take place first it must be established if adaptations to methods can enable adults with SSPI to take part in User Centred Design.

The aim of this study is to determine the degree to which adults with SSPI can be involved in the design of software to facilitate communication processes, by adopting a User Centred Design paradigm.

The research questions in this study are:

1. Can the problems cited in the literature be overcome to allow User Centred Design to be conducted with participants with SSPI?
2. Can methods currently used in Human Computer Interaction be combined and adapted to allow people with SSPI to contribute to the design of technology?

The first research question focuses on how the problems cited in the literature are dealt with throughout the user centred development of software while the second investigates the degree of involvement of the users. The degree of involvement will include a measure of the different contributions in each stage of the process.

4.8 Summary

This chapter built on the discussions in Chapter Two and Chapter Three on SSPI, AAC and User Centred Design, it introduced a review of the literature which shows that to date no study has included adults with SSPI actively in all stages of the User Centred Design process. It has also highlighted the problems which are discussed in the literature on conducting User Centred Design with adults with SSPI. This chapter concluded with the rationale for the research question which will be investigated in the remainder of this thesis. The first step will be to evaluate the suitability of existing User Centred Design methods for this population and the ways in which they will be adapted (see Chapter Five). Following this a pilot study involving adults with SSPI will be conducted (Chapter Six).

Chapter 5. Methods in Software Development with Adults with SSPI

"What we're saying is, what we want the most, is inclusion"

Robert, a participant in the study with SSPI

5.1 Introduction

In order to answer the research questions a software development project with User Centred Design was planned. This chapter provides an overview of the methods in User Centred Design along with a discussion on their suitability for participants with Severe Speech and Physical Impairments (SSPI) will be discussed. Possible adaptations to these methods are also suggested.

Many of these methods can be used in multiple stages of the User Centred Design lifecycle (see Chapter Three) and so are categorised by theme rather than grouped according to the lifecycle stages.

5.2 User Centred Design Methods

User Centred Design methods differ from other software development methods (e.g. performance measurements which investigate the speed software can automate a task (Sharp et al., 2007)) in that they include participants.

5.2.1. Ethnographic Methods

Most software developers have limited experience of SSPI or how the environment that people with SSPI live in (e.g. care centres) operate (Waller et al., 2005a). It would therefore seem logical to meet people in the environment, observe the day to day workings of a centre and perhaps become involved in some of the centre's

activities. When these methods are used the process becomes known as ethnography (Hughes et al., 1994).

Ethnography is now becoming an accepted process in HCI with one of the most famous examples coming from the 1970s (Suchman, 1987) when a study was conducted into the use of the electronic help system of a photocopier. By the use of ethnographic methods, HCI researchers can understand the context surrounding the information's location and users.

The two main methods in the ethnographic process are observations and focus groups:

The use of observation for the user centred design phase of 'context of use' with adults with SSPI is not new (O'Connor et al., 2006), however previously it has been in the form of non-participant observations. Previous studies have shown the value in conducting ethnographic research with people with disabilities (e.g. Davidson, Howe, Worrall, Hickson, & Togher, 2008; Gordon, Ellis-Hill, & Ashburn, 2009).

Focus groups are now used as a means of evaluating the experiences of people with health and social services and in action research projects (Kitzinger, 1994; Willson et al., 2005). Focus groups are also commonly used in requirements gathering to identify the requirements from different groups of people and discuss any conflicting wishes in the design, but can be used in any stage (Nuseibeh and Easterbrook, 2000).

Focus groups are useful in gathering many different views on a topic and insights into people's shared and different opinions (Gibbs, 1997). In a focus group the discussion between participants and sharing of views may lead to a greater disclosure and volunteering of information; it also allows a researcher (or designer) to discover

why a participant holds a certain view (Gibbs, 1997). Participants may be encouraged or reminded of something they wish to share as they piggyback on each other's statements (Rennekamp and Nall, 2000).

Focus groups can be difficult to analyse and it can be difficult to get all of the participants to participate (Krueger and Casey, 2009), often one or two members can dominate the discussion.

Focus groups are now becoming more common in HCI as can be seen by recent panels and workshops at conferences such as ACM CHI (Rosenbaum, Cockton, Coyne, Muller, & Rauch, 2002).

There is evidence from the social and health fields of adults with SSPI being involved in focus groups (Hemsley et al., 2008b, Dattilo et al., 2008) and it would appear that with careful planning it should be possible for this to translate into the HCI area.

5.2.2. Interactive Methods

Interactive methods involve the participant and the researcher discussing topics and engaging with one another. They are useful because they allow the researcher the opportunity to probe further into why a participant thinks a certain way, but there is the risk that if a good rapport cannot be established between the participant and researcher that little data will be collected (Cartwright and Cartwright, 1974)

Forum Theatre

A forum theatre performance will generally consist of a short drama designed to spark conversation and feedback from the audience on what they have just seen (Boal, 2000). It will typically have some form of controversy and stop at the critical

point to encourage audience members to participate. Its use as a requirements gathering method in computer design is increasingly being recognised (Newell et al., 2006a).

Forum theatre is particularly suited when the technology being designed does not yet exist as it allows participants to imagine how it might be used (Rice et al., 2007). The disadvantage of forum theatre is that participants might become totally focussed on the characters in the film and will not be able to generalise (Carmichael et al., 2005).

Forum theatre would seem useful for participants with SSPI to help them visualise the situation and to feel more comfortable sharing their views (Newell et al., 2006b).

Storyboarding

Storyboards were first used in the film industry to represent the major sections of a scene, when arranged in order it helped the film crew to visualise the film (Kinchin et al., 2000).

In software development the storyboards depict visually the interaction between the user and the system (Leveson, 1995). Storyboards can be sketched quickly as stick people or can be crafted more elaborately. Storyboard can be created quickly but they can also become out of date quickly.

Storyboarding allows requirements to be captured in graphical form rather than in text. Storyboards explore alternatives to what already exists or to test the feasibility of an approach (Kinchin et al., 2000).

Storyboarding would appear to be a good fit for use with participants with SSPI as they can help the participants visualise the new technology being developed and help to prompt for new requirements.

Interviews

There are three major forms of interviewing: unstructured, structured and semi-structured (Britten, 1995). Unstructured interviews take the form of a general conversation around a particular topic and tend to be exploratory in nature whereas structured interviews are composed of predetermined questions and do not deviate from these. Semi structured interviews will have a combination of open and closed questions (Lazar et al., 2010).

When working with adults with SSPI interviews can be useful in providing them with the time they need to formulate an answer, but the researcher must ensure that the participant knows them and is comfortable with them so that they do not become overly anxious which can affect communication (Beukelman and Mirenda, 1992). If interviews are being used early in the process there is the difficulty of helping participants to imagine new technology and pre-prepared tools for prompts may assist with this.

5.2.3. Testing Methods

Testing methods will typically be used towards the end of a development to judge how effective the system is. They may however, also be used at the beginning to investigate how well existing technology can perform tasks.

Usability Testing

Usability testing is usually used in the latter half of the product lifecycle when evaluating prototypes and designs (Battleson et al., 2001). There are a number of measures that can contribute to this testing including: time taken to complete a task,

number of errors made etc[9]. Usability testing can provide quantitative figures to produce statistical results on improvements in task performance with the new system (Nørgaard and Hornbæk, 2006). Usability testing can be expensive and time consuming and there is the risk that users may feel they are being tested (Virzi, 1992).

It is likely that several modifications would be required to allow this method of evaluation to be used with participants with SSPI.

Think Aloud

Think Aloud is usually used in evaluations when participants are using the system (Sharp et al., 2007). In think aloud a participant is asked to speak aloud their thoughts as they complete tasks on a system.

Think aloud can feel awkward to participants and many complain that it feels unnatural (Nielsen et al., 2002). It also has a high cognitive load (Lazar et al., 2010).

For participants with SSPI there is first the practical problem of how they would communicate on a device while using the system they are evaluating, there is also the significant concern on the extra cognitive load it requires.

5.2.4. Prototyping

There are three levels to prototyping: low fidelity, mid fidelity and high fidelity (Blum et al., 1991). Co-design prototyping where participants are involved in shaping the design is confined to the designing stage of the User Centred Design lifecycle (Westerlund et al., 2003). Prototypes which are created by the designers and used in requirements gathering have been used successfully in studies in the past

[9] For this thesis the term error is used to indicate a situation in which a user is unable to complete a task. A situation where a user takes a path through a task which is unexpected but still arrives at the specified end point and completes the task is not considered an error.

(Rudd et al., 1996) but this comes with the risk that participants will be led by the prototypes.

Low-fidelity prototypes are often made from paper screen mock ups, when a user selects an option on the paper, the researcher or designer will then place another piece of paper with the results of the action displayed on it (Blum et al., 1991). Low fidelity prototypes are most useful at the beginning of the design process to understand better how a user will interact with the system and to identify any major design problems early on (Blum et al., 1991). Low fidelity have the advantage of being created quickly and cheaply, but are less useful for user evaluation as they do not simulate user interaction well. High-Fidelity prototypes will look more like a final device and are very useful for looking at interaction, however as with evolutionary prototypes there is a danger that users will be unwilling to give criticism as the prototypes will look finished(Rudd et al., 1996).

When using prototypes for adults with SSPI it may be best to start with lower fidelity prototypes so that participants are more likely to give criticism from the beginning of the project. If participants are shown high fidelity from the start there may be a reluctance to give criticism for fear of offending the developer of a finished product.

5.2.5. Indirect Methods

Indirect methods will often involve asking the participant to provide information without ever having met the researcher or with them only present for the taking of informed consent and explaining the method. The advantage is that the participant may feel more comfortable sharing their opinions when they are not in direct contact with the researcher (Sharp et al., 2007). These methods do not allow the researcher to probe further into a participant's view.

Diaries

When using diaries, participants are asked to record their thoughts or experiences on a particular subject, this method can be used before design commences to evaluate an existing experience or later during the system evaluation to see how well it worked in situ (Lichtner et al., 2009). Diaries can be useful as they allow self-reflection by the participants, but they are often forgotten or neglected and are not a rich source of information (Dickinson et al., 2007).

Diaries could be problematic for participants with SSPI who are likely to have problems with motor control for writing and may also have literacy problems (Glennen and Descoste, 1997). One possible adaptation is that the diaries could be produced on a computer which may reduce some of these difficulties.

Questionnaires

Questionnaires are similar to interviews in that they can have open and closed questions, they can be used at any stage of the development lifecycle (Griffith et al., 1999). Questionnaires have the advantage that participants may feel more comfortable answering personal questions when they are not directly communicating with the researcher but the researcher is not usually available to clarify queries which may lead to confusion over what the question is asking (Goodman, 1997). Participants who are not clear on what a question is asking may omit to answer it, this can cause problems when looking for statistical evidence from answers.

When working with participants with SSPI, researchers must ensure the questions are easy to understand and may need to develop new ways of providing the questions and getting answers so that participants who are not literate can answer them. Having

someone else read the questions and write the answers may reduce some of the benefits of questionnaire in allowing participants to respond privately.

5.3 Choice of Methods

The methods and the sections of the User Centred Design lifecycle that they are suitable for are detailed in Table 3.

Table 3 - Methods Available for Sections

Method	**Identify Context of Use**	**Gather Requirements**	**Produce Designs**	**Evaluate Design Against Requirements**
Diaries	*	*		*
Interviews	*	*	*	*
Usability Testing				*
Questionnaires	*	*	*	*
Think Aloud	*		*	*
Forum Theatre		*		
Storyboarding		*		
Prototyping		*	*	
Focus Groups	*	*	*	*
Observation	*	*		*

Having looked at all these methods it is necessary to see if the reasons for not using them with participants with Severe Speech and Physical Impairments are valid. In order to do this, a User Centred Design software development project was undertaken to develop a multimedia patient profile.

5.4 Summary

This chapter introduced the major methods used in User Centred Design were presented and their suitability for use with participants with SSPI was discussed.

It became apparent that not all of the methods commonly used would be entirely suitable for this user group and the choice of which methods to use was taken seriously and given careful consideration.

Chapter Six will discuss how the methods were implemented and the effect they had on shaping the software being developed. Chapter Six will also discuss the means by which ethical approval for the project was granted and how informed consent was given by participants with SSPI.

Work from this chapter contributed to a paper presented at the ACM CHI 2010 Conference (see Appendix A)

Chapter 6. **Creation of CHAMPION Software with Adults with SSPI**

"What we do matters".

Doug, a participant in the study with SSPI

6.1 Introduction

This chapter looks at the development of an Assistive Software program using User Centred Design with adults with Severe Speech and Physical Impairments (SSPI). Background information on the software developed and the rationale for choosing it is outlined at the beginning. This is followed by a discussion of the ethical problems in working with adults with SSPI that had to be overcome before work could commence.

For each method used in the different stages of the User Centred Design lifecycle, a description of the method used and the adaptations made are described. Following this, two separate sets of results are provided, these results related to the two different research questions.

6.1.1. Research Question One

The first research question investigated if the problems cited in the literature could be overcome to allow User Centred Design to be conducted with participants with SSPI. The results for this question report on the way participants responded to methods, their ability to work as co-designers and the input they had.

6.1.2. Research Question Two

The second research questions investigated if methods currently used in Human Computer Interaction (HCI) (see Chapter Five) could be combined and adapted to allow people with SSPI to contribute to the design of technology. The results to this

question are grounded in HCI theory and report on the requirements given or the design alterations requested.

Following each stage in this chapter a review is presented of what worked and what did not work in the stage.

This chapter concludes with details of the debrief of the participants on their reflections of participation in the project.

Following this chapter a discussion is presented which looks at the lessons learnt in the development and how they can be used by other developers.

6.2 Choice of Assistive Software

As was established in Chapter Two, the poor usability of software in Augmentative and Alternative Communication (AAC) devices is linked to the high rate of abandonment and there are suggestions that if User Centred Design could be conducted in the development of this software then the usability could be improved. In order to investigate how User Centred Design could be conducted with end users of AAC (adults with SSPI) the author decided to produce a piece of software that would allow users of AAC to share information. It was not the aim of this research to produce software that was fully functioning and capable of communicating and there is evidence in the literature that a 'Communication Partner'[10] can influence the satisfaction a user gains from the AAC device (Kent-Walsh and McNaughton, 2005). Instead it was decided to develop a tool by which users with SSPI could store and share information about themselves without requiring a communication partner.

[10] A communication partner is someone who sends and receives messages with the person in question (Kent-Walsh and McNaughton, 2005)

The software chosen for development was an Electronic Patient Communication Profile, this met the criteria of allowing a person with SSPI to share information without a communication partner and was also a piece of software which was reported as being needed by this population.

6.2.1. Background to Electronic Patient Communication Profiles

This section provides a brief rationale for the choice of software. A fuller explanation is provided in .

A visit to hospital is traumatic for both a disabled patient and family members, especially when the patient has no or limited functional speech (Bartlett et al., 2008).

Adults with SSPI, in particular those with cerebral palsy, are 2.2 times more likely to attend an outpatient clinic than their peers with no disability and have a 10.6 times higher risk of being admitted into hospital as an inpatient (Young et al., 2007). Recent research with adults who are unable to speak in hospital has indicated that hospitalisation presents special challenges to both the families and the staff who care for the patient with moderate to profound communication impairment (Hemsley et al., 2001, Hemsley et al., 2008a, Hemsley and Balandin, 2004). Adults with SSPI are at higher risk of suffering from a preventable accident or medical error while in hospital (Zinn, 1995).

Currently the most commonly used method for assisting medical staff is a paper care book compiled by the care attendants of the adult with SSPI, providing information on their needs and habits (Millar, 1997). However, these have generally been overlooked by nurses, and patients themselves feel they are of little, if any use (Hemsley et al., 2001). The use of multimedia as a form of advocacy is gaining popularity amongst adults with SSPI or learning disabilities, and has been well

received by professionals using it to make decisions on care for the adult involved (Grove, 2003).

There have been a suggestion in the literature that Electronic Patient Communication Profiles could help with this problem (Prior et al., 2009). This software fitted the requirements in section 6.2 in that it allowed a user of AAC to share information about their life without requiring a communication partner, and was chosen by the author for this pilot.

6.3 Planning the HCI Process for Adults with SSPI

When planning the HCI process, the first step is to consider the ethical issues in the study and to gain ethical approval (Molich et al., 2001). When working with participants with SSPI there is a high chance that ethical approval will have to be granted by a NHS ethics committee as many of the day and residential centres for adults with SSPI are run by the NHS or a local authority (Department of Health, 2003). Any time that NHS or Social Care resources (e.g. staff, buildings or service users) are used in a project it must be given approval by a NHS Ethics Committee (IRAS, 2011). When work is being carried out outside of the NHS, approval should come from an internal ethics board.

The Communication Hospital and Multimedia Patient Information Organisational Network (CHAMPION) project had ethical approval from both the internal University Ethics and the NHS Tayside Ethics Committees. In total there were three main alterations to a traditional ethics procedure (see Figure 5).

6.3.1. Capacity to Consent

Gaining informed consent from participants involved in research is seen as one of the most important aspects of ethical research (Mauthner et al., 2002).

When working with adults with SSPI in research there are two main issues to consider in relation to this. Firstly, gaining consent must provide participants with the opportunity to ask questions and when working with participants with SSPI, researchers must devote considerable extra time to allow for this and to ensure participants feel confident in asking all of their questions. The other issue is, given that participants may have some level of cognitive impairment how can researchers be sure that they are fully aware of what they are agreeing to (Balandin et al., 2006).

Adults with SSPI are at a higher risk than the general population in having a literacy impairment (Millar and Kerr, 1998, Pagulayan et al., 2003). Terms in consent forms and participant information sheets may contain technical and/or experimental terms which are unfamiliar to those with no previous experience of participating in research projects (Dickinson, Arnott, & Prior, 2007), and confusing to those with a lower rate of literacy than those who traditionally participate in research projects, such as students.

The modified consent process by Balandin et al., (2006) uses a series of multiple choice questions which the person responsible for taking the consent should ask a participant. All of the questions should be answered correctly for it to be classed as informed consent (Balandin, Berg, & Waller, 2006). This was used by the author throughout the study.

6.3.1. Stress on Participants

The NHS Tayside Committee was concerned that being asked to work on a piece of technology that had not yet been created would put too much of a strain on participants.

The author made it clear to the committee that they would attempt to minimise this as much as possible and would reassure participants frequently that there was no wrong answer and would be careful to watch for signs of fatigue.

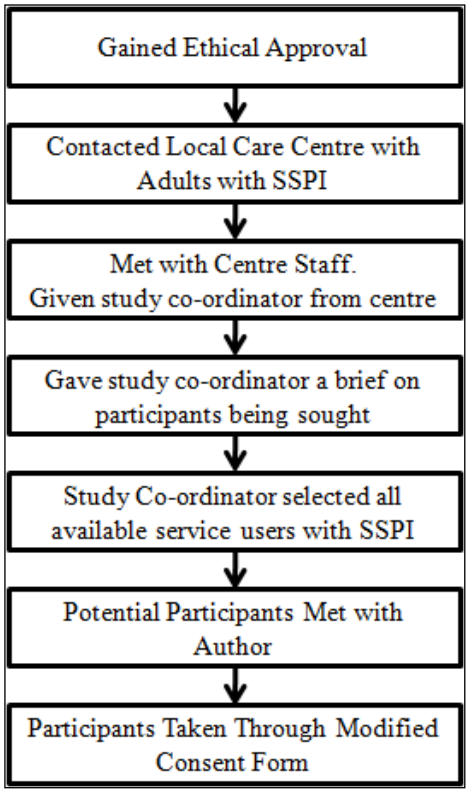


Figure 5 - Ethical Procedure in CHAMPION Development

6.3.2. Recruitment of Participants

Traditionally participants would be recruited through adverts in the local press or University or by being contacted directly from researchers who have been given their contact details by organisations (Krueger and Casey, 2009). These methods are not best suited to working with adults with SSPI. Firstly many people with SSPI have literacy problems (see Section 6.5) and secondly the author did not want to distress people by inviting them to take part and then discover that the participant was not capable of providing informed consent, and have to tell them that they could not actually participate.

Contact was made with a local centre for adults with a variety complex disabilities including SSPI. The centre management was provided with details of the study. The management then provided a site specific study co-ordinator to be the liaison on the project. The author met with the study co-ordinator and gave further study details and asked them to consider potential participants. The study co-ordinator met with potential participants and with their consent arranged a meeting between them and the author.

In this meeting the author went through the NHS Patient Information with the potential participants, discussed the activities they would be invited to take part in and what their rights in the study were. The participants were encouraged to ask questions and were then taken through the modified consent process.

The study co-ordinator attempted to select a representative sample of participants but the number of adults with SSPI who had the ability to consent was limited. There was a spread of ages, genders and means of communication but the sample could not be classed as a true representative sample.

Once ethical approval had been granted, the User Centred Design cycle could begin (see Chapter Three). The methods used in each stage of the User Centred Design cycle are shown in Figure 6.

6.3.3. Potential for User Centred Design with Adults with SSPI

The NHS ethics committee approved this process and this method of gaining participant consent. The study co-ordinator was able to consider the requirements for participants and selected as representative a sample of participants as possible. The staff co-ordinator would appear to be a good judge of the potential for participants to

be able to consent as all of the potential participants were able to pass the informed consent questions and provide informed consent.

6.3.4. Potential for Adapted Methods to Allow Adults with SSPI to be Participants

The participants were able to complete the adapted consent forms. Initially participants were reluctant to ask questions on the information sheet and consent form, however thanks to the assistance of the staff co-ordinator they were encouraged to give serious consideration to their rights and responsibilities in the study. All of the consented participants asked at least one question regarding the study (e.g. "*What would you do with the work I have already done if I stop coming to meet you?"*).

6.4 Identifying the Context of Use Through Observation

In this stage the aim is to identify the users' attributes, the organisation environment and the current tasks the user performs (ISO, 2010).

The author, in common with most software developers had limited experience of how care centres for adults with SSPI operated. The author decided to spend time at the centre to learn more about this environment. The primary aim of the observation was to gain an understanding how the environment operated and the characteristics of people in the environment.

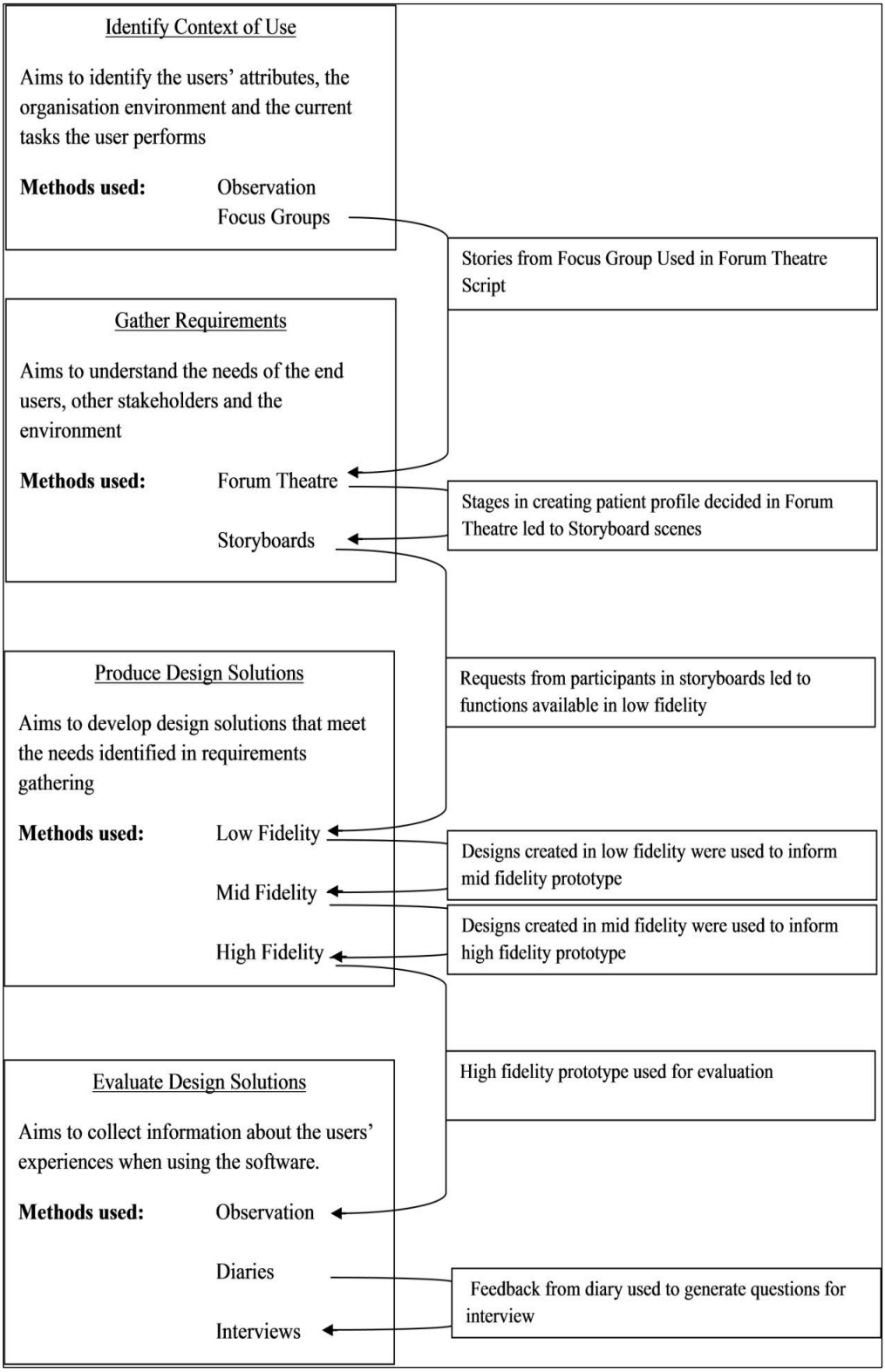


Figure 6 - Methods Used in Development Process

6.4.1. Method

A major challenge for the ethnographic researcher is becoming immersed in the environment and being seen as a member of the environment. Researchers must decide on the degree of participation they will take in the environment (Hammersley and Atkinson, 1994). In some studies ethnographers hide their identity while in others they merely observe, although it could be argued that only observing is not strictly ethnography as the researcher is not participating in the environment (Hammersley and Atkinson, 1994).

In the care environment, concealing the author's identity would not be ethical or safe. The author declared to everyone her role but became immersed in the environment by providing assistance to staff and residents alike, for example helping with setting up devices or making coffee. This avoided the risk of missing out on vital information by becoming a complete observer (Gold, 1958). Using Gold's categorisation (see Figure 7) the current author took the role of "participant-as-observer" (Gold, 1958).

Complete Participant- Researcher's identity and purpose is not known to those being observed.

Participant-as-Observer – Identity is known by those being observed. Researcher takes part in community.

Observer-as-Participant - Identity is known, more formal, less direct interaction with those being observed.

Complete Observer – Identity is known. No direct interaction with participant.

Figure 7 - Forms of Observation

Field notes were taken throughout the observations and a digital camera was used to record incidents of note, such as a participant demonstrating how they currently carry out a task on the computer (see Figure 8).

To begin an ethnographic study the researcher must build a relationship with participants in the group. The author started with the study co-ordinator provided by the care centre and relied on her to make the initial introductions. Gold (1983) cautions that relying on one member of an environment to make introductions can open the researcher to a real risk of bias by only meeting people whom the initial member wishes them to (e.g. colleagues with the same perspective on issues being investigated). The author was careful to avoid the risk of bias as much as possible by asking to be introduced to a variety of people. A care centre will generally be used to a high staff turnover and used to new people arriving (Cumella and Martin, 2000). The staff at the care centre adapted very quickly to the current author's presence and after the initial few sessions they began to treat her as a member of staff.

The study coordinator offered to allow the author to join them in their usual work, look around the different facilities and observe activity sessions to see how these facilities were used and talk to service users and how they felt using technology.

6.4.2. Potential for User Centred Design with Adults with SSPI

The participants were very welcoming towards the author and were eager to engage in conversation, particularly when it was on a one to one basis. One participant informed the author that he did not often get an opportunity to engage with people from outside the centre and that he was always glad of the chance to be involved in conversations.

The staff were more cautious initially but after the first two days would willingly talk to the author and shared their opinions on technology and how the centre members could use it.

The adults with SSPI were able to explain to the author how the centre operated and showed her around the centre explaining how things worked.

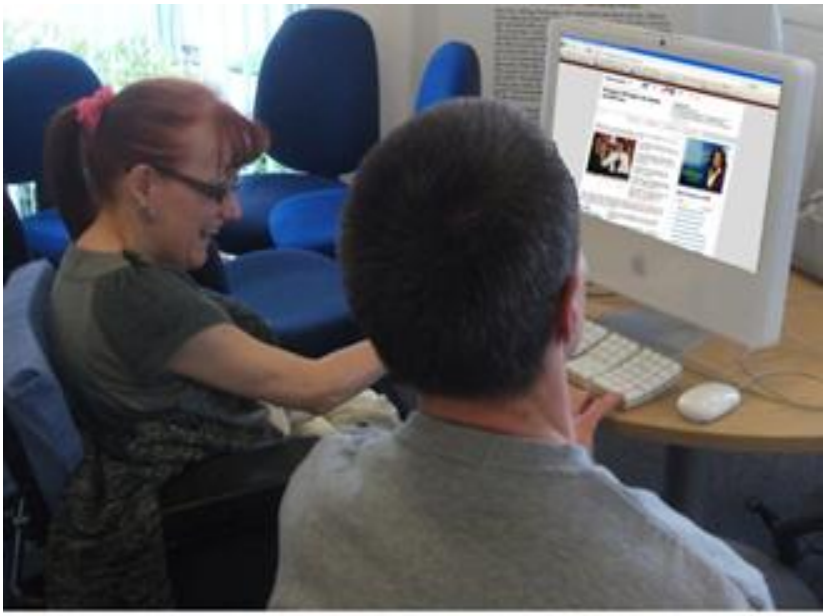


Figure 8 - Participants Demonstrating Current Use of Computers[11]

6.4.3. Potential for Adapted Methods to Allow Adults with SSPI to be Participants

This method did not generate many concrete results. Instead it gave the author a better understanding of the participants' needs and the roles the different members of staff played.

6.4.4. Review of Observation

In order to further understand how service users felt about the idea of using software such as the patient profile and to enable them to discuss problems they had

[11] To protect the anonymity of participants, actors with SSPI have been used to recreate the original scenes in some photographs

experienced in which the software might have helped the methods employed by the end users to communicate. The focus group would also help the author to understand more about the characteristics of the end users.

6.5 Focus Groups with Adults with SSPI

Work from this stage contributed to a paper in The Journal of Behaviour and Information Technology (see Appendix C*).*

Focus groups have been used successfully with adults with SSPI in the fields of health care and social studies (e.g. Hemsley et al., 2008a), but to date have not been used with this user population in HCI (Prior et al., Accepted).

6.5.1. Method

After an examination of the current state of the field for focus groups with adults with SSPI (Prior et al., Accepted) and in light of the lack of guidelines available, the author looked at the general additional considerations when working with adults with SSPI.

Communication Considerations

Focus groups centre around the communication interaction between participants (Morgan and Krueger, 1993) but this can pose problems for adults with SSPI.

People who use a high tech AAC device for communication may produce words up to 25 times slower than those with normal verbal speech (Higginbotham, Bisantz, Sunm, Adams, & Yik, 2008). The time therefore for a participant to reply, for example “Yes, that has happened to me” could take up to two minutes for a participant relying on AAC (Augmentative and Alternative Communication at the University of Washington, 2009).

For those participants using low tech AAC, a facilitator is likely to be required for the focus group. The facilitator would have to follow the participant's finger pointing and speak the message on their behalf (Prior et al., Accepted)

Literacy Levels

As discussed in Section 6.3.1 participants with SSPI may have low or limited literacy and in focus groups participants are often to take their own notes on certain discussions or be given 'prompts' to help with the discussion. These prompts will often be newspaper articles or written scenarios and discussions (Krueger and Casey, 2009). It may be necessary to consider what if any prompts can be used with participants with SSPI.

Concentration Levels

People with cerebral palsy or traumatic brain injury (two of the major causes of SSPI) are likely to become tired more quickly than the general population (Wood et al., 2008, Jahnsen et al., 2003b). The average length of a focus group is between ninety minutes to two hours (Kitzinger, 1995; Krueger & Casey, 2009); this will require an extended period of concentration and people with SSPI are likely to fatigue in this time.

Physical Considerations

Focus Groups have traditionally been conducted around a table (Krueger & Casey, 2009), with a moderator at one end of the table and possibly a moderator's assistant at the other, the assistant has the role of taking notes.

Participants with SSPI are likely to have a range of motor impairments, which may restrict their ability to sit at the table and/or may require them to use a wheelchair (Finnie & Bavin, 1997).

As a focus group is primarily a study of the interaction between participants (Morgan & Krueger, 1993), the layout of a group requires careful consideration to ensure that participants are positioned in a way that encourages conversation and debate.

Table 4 - Participants in Focus Group (Pseudonyms Used)

Participant	**Method of AAC**	**Other Means of Communication**	**Established Group Membership**
Danni (29)	Lightwriter AAC Device	Vocalisation	Lives at resource centre
Robert (58)	Gestures	Dysarthric Speech	Attends resource centre three days a week
Doug (53)	Dynavox AAC Device	Dysarthric Speech	Attends resource centre four days a week
Patricia (44)	Signing	Dysarthric Speech	Attends resource centre five days a week
Lisa (40)	Facial Gestures	Dysarthic Speech	Attends resource centre four days a week
Sam (30)	Hand gestures	Dysarthric Speech	Attends resource centre two days a week

6.5.2. Participants

For this innovative focus group, six adults with SSPI who were capable of giving informed consent using the process described in Section 6.3.1 and who received services at the care centre either as day users or residents were recruited through the study coordinator at the centre (see Table 4). The study coordinator was asked to recruit as wide an age range as possible with an equal split of males and females. It was also hoped that participants would use a mix of communication methods. While again this could not be considered a true representative sample, it was hoped that the credibility of the convenience sample could be as high as possible.

The group of participants ranged in age from 29 to 58 and were composed of three female and three males. Five of the participants were day users of the centre and one was a resident user.

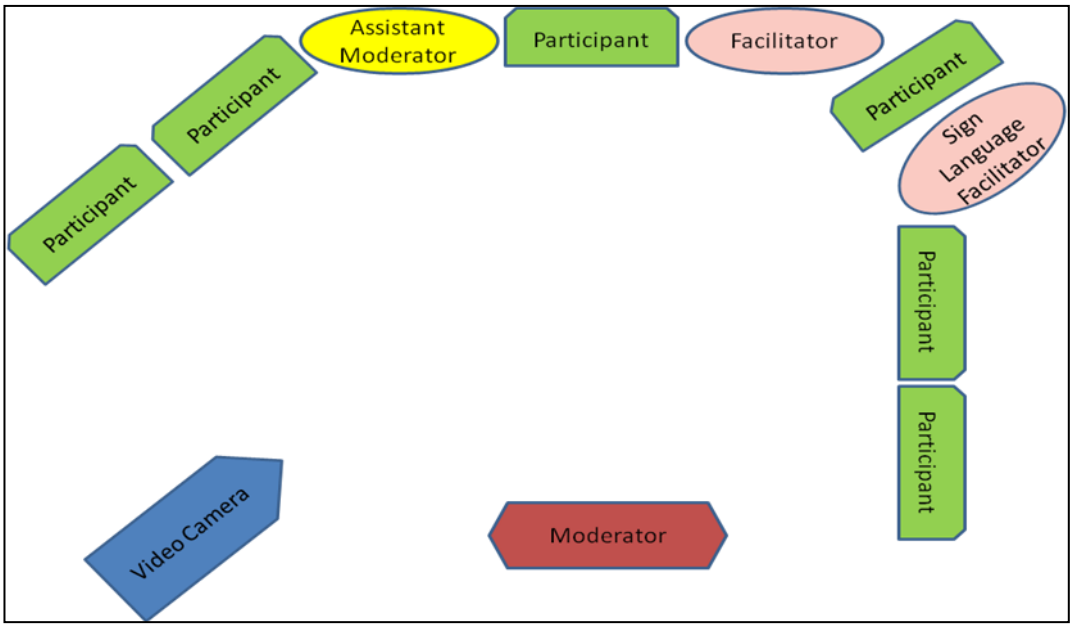


Figure 9 - Layout of Focus Group

6.5.3. Layout of Focus Group

The focus group was held at the centre in a room used for activity sessions. As all of the participants used motorized wheelchairs a semi-circle was formed with

facilitators placed next to the participants who required the most help with their communication. One participant had a hearing difficulty in addition to his speech impairment so a facilitator was sat next to him at an angle to allow for better communication of the questions and to assist with signing of questions.

The moderator sat at the top of the semi-circle with the video recorder placed to the left of the moderator to ensure all the participants were in view (see Figure 9). The moderator's assistant sat opposite the moderator and took notes throughout the session.

6.5.4. Format of Session

Participants were asked for their experiences of sharing information with medical professionals (see Figure 10). This would give further information to complement the information in the literature on electronic personal care records.

Figure 10 - Participants In Focus Group Discussing Bad Hospital Experience

Due to the increased chances of fatigue the session only lasted sixty-two minutes with a further seven minutes for debriefing. Participants were told they could take a

rest or leave at any time. During the session, one participant chose to leave for twenty minutes and returned before the end of the session.

The number of questions in the session was significantly less than the usual number of questions that would be set in a focus group (Krueger & Casey, 2009), only three questions were covered:

1) What good experiences have you had in hospital?

2) What bad experiences have you had in hospital?

3) What information would you like to share with medical staff.

This was for two reasons: to reduce the cognitive demands on participants and to allow participants longer to prepare their answers.

The moderator did not detect problems or impatience from the respondents and in general the participants did not interrupt one another. The moderator was only required once to stop a participant from talking until the other had given their reply.

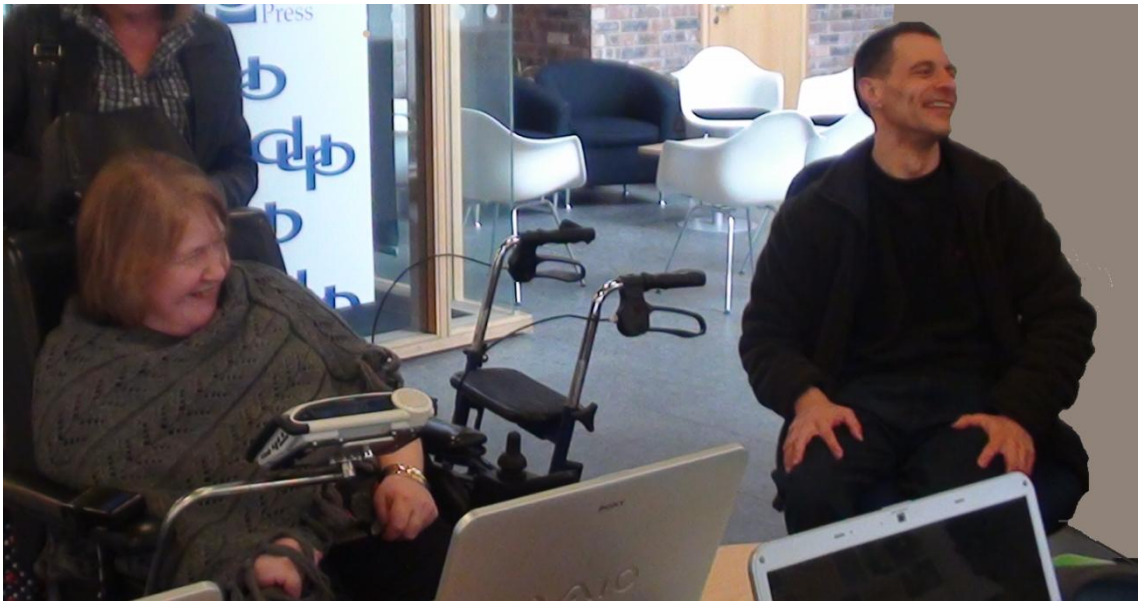


Figure 11 – Participants During Debriefing

6.5.5. Debriefing of Participants

Frequently in focus groups, a written summary or even the full transcript will be provided to participants after the focus group session (Hemsley et al., 2007, 2008b). Given that the participants had varying levels of literacy (ranging from no functional literacy to reading age 16), the feedback was provided orally at the end of the session by the moderator's assistant (see Figure 11).

6.5.6. Results of "Potential for User Centred Design with Adults with SSPI"

An examination of the transcript was conducted using coding (see Appendix C) and was verified by an independent researcher.

Participants were initially hesitant in answering questions and only gave short answers in reply to a direct question. After the first eighteen minutes participants began to directly engage with each other with only minimum input from the moderator to move onto the next question or to bring the conversation back on topic.

Author: can you think of anything else?

Danni types: to talk to me more

Doug: would you like them to have a chat with you

Danni types: yeah

Robert: talk to the organ grinder not to the monkey

Patricia: they always talk to someone else and never get time to talk to you.

Robert: I find it so frustrating when they don't talk to me on the ward and they ask someone else and I think for god's sake ask me. It's so frustrating

Lisa: I thought you were going to say something else Robert

Author: so that really annoys you when they don't speak to you?

Patricia: yeah

The time spent on each question increased during the session from an initial three minutes on the first question to a peak of twenty-six minutes on the third question.

This transcript shows that 47% (n = 43) of the utterances by participants were unprompted and that all participants responded unprompted at least once (see Figure 12). For two participants, the number of unprompted responses outnumbered their prompted responses.

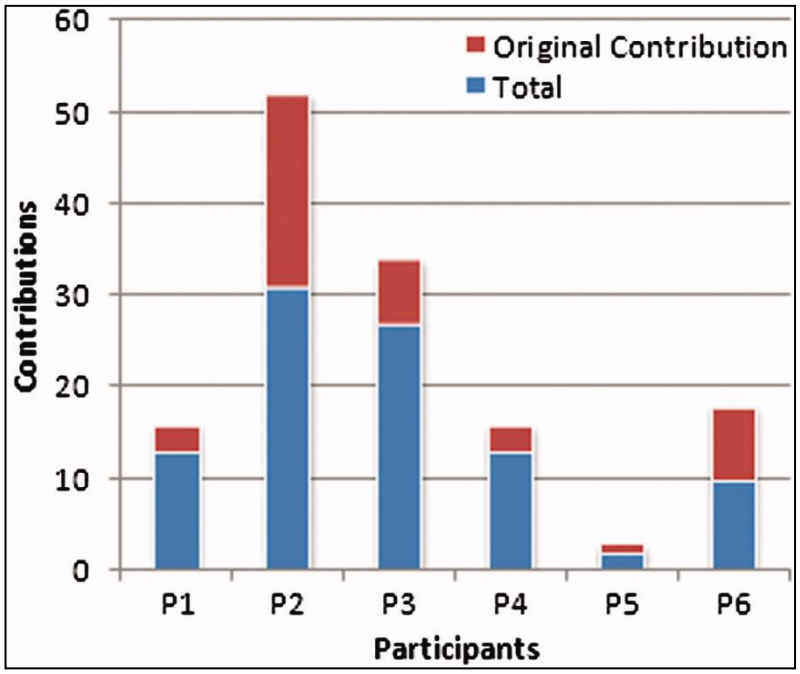


Figure 12 - Responses of Participants (Prior et al., Accepted)

The other interesting result from the transcript was that the three participants who responded the most were the three with the most severe communication impairment. The feedback section of the focus group was the most animated of the hour with

participants agreeing both vocally and with nodding of the head that the account was accurate. The summary section of the session finished with one participant saying:

"*One last thing, thank you for listening"*.

Kitzinger (1994) suggests that one of the defining features of a focus group which differentiates it from a group interview is the examination of the interaction between participants. During the focus group session, the participants with SSPI were able to interact with each other and many of the ideas that they generated emerged as a result of discussion with and suggestions by other participants. Often one participant would share a story relating to an experience and this would prompt another to think of a similar story or offer suggestions on how a piece of technology could have helped them there:

> **Doug**: They don't know how I drink
>
> **Robert**: see I was the same see when I first came out of the coma, I asked for a drink so they gave me my liquids with a straw but I didn't have the muscles in my throat to suck so eventually I said "here" the doctors they got me a drink through a syringe cause I could not suck. But it took a long time to get a drink.

6.5.7. Results of "Adaptation to Methods in Enabling Adults with SSPI to be Participants"

The aim of the Focus Group was to understand the context of use, in particular the issues surrounding the need for the software. Participants were asked three questions related to their own experiences of sharing information with medical staff. The first question related to good experiences. Only one answer was provided, two of the participants felt that the food in the hospital was good. The next question asked

participants about negative experiences, participants related their personal experiences to this theme and shared stories about AAC devices being removed and lack of communication between the doctor and the patient. One example of this came when participants discussed the way they perceived the doctors thought about them:

Doug: The doctors speak to you as if you have a mental problem

Staff Liaison: do you mean an intellectual problem?

Doug nods

Robert: I can relate to that

Author: Has that happened to you to?

Robert: I think what Doug is trying to say is that they think you have aren't smart

Doug nods

Staff Liaison: Do you think people look at you Robert?

Danni makes noise to get attention.

Danni types.

Danni types: looked at step mum .

Robert: they think ah he doesn't have a mind of his own

The third and final question related to the current information sharing tasks that participants struggled with in hospital. Participants stated that they struggled to share information on anything in hospital but following discussion they identified six key

areas: mobility, personal care, food and drink, getting staff's attention, having AAC devices removed and assumptions on their cognitive ability. In all of these areas the discussion went into detail of the problems and provided useful scenarios and vignettes which could then be used in the requirements gathering stage (see Section 6.7).

6.6 Review of Establishing Context of Use

During the establishment of the context of use the main aim was to learn more about adults with SSPI and the care environment. The ethnographic process was used for this and allowed the author to become embedded in the environment, not only allowing a better understanding of the way the environment operated but also preparing staff and centre users for her continued presence during the crucial requirements gathering and development phases.

The focus group was used to gather more information on the hospital experiences of adults with SSPI, to help the author understand the personal stories behind the rationale for the development of a multimedia patient profile and also allowed the author to spend a concentrated amount of time with the participants to get to know them better. The next stage was to establish the requirements for the software.

6.7 Gathering Requirements Through Forum Theatre

The aim of requirements gathering was to understand the needs of the end users, other stakeholders and the environment. The decision had been made to use Forum Theatre and Storyboarding techniques in the gathering of requirements. These techniques have been shown in the past to be of particular use when the technology

being designed is completely new or when participants providing requirements have traditionally not been involved in research (Rice et al., 2007).

As discussed in Chapter Five, forum theatre was developed by Boal in Brazil and is described in this book "Theatre of the Oppressed" (Boal, 2000). It will typically have some form of controversy and stop at the critical point to encourage audience members to participate. It's use as a requirements gathering method in computer design is increasingly being recognised (Newell et al., 2006a).

Software designers who have experience in using forum theatre as a means of requirements gathering believe the advantages from forum theatre lie in its ability to facilitate discussion of sensitive topics with potential users and cover several potential uses for a system in one cohesive storyline (Carmichael et al., 2005). Forum theatre also allows audience participants to suspend disbelief and imagine how a piece of technology that may not be in existence at present could be used in the future (Carmichael et al., 2008). Forum theatre has been used in video format for software design in the UTOPIA video trilogy (Eisma, et al., 2004).

The use of forum theatre video with the participants with SSPI aimed to gather requirements on the types of information participants would want stored on the CHAMPION system. This information would be based around the problems adults with SSPI face when admitted to hospital.

6.7.1. Creation of Material for Forum Theatre

Stories from the Focus Group described in Section 6.5 were examined alongside reports in the literature on problems surrounding hospitalisation for adults with SSPI. The author created two possible scenarios (see Figure 13 and Figure 14). The scenarios were then given to a professional script writer and director with experience

in forum theatre. The video was produced using two actors with SSPI and two professional actors. Full details on the production were presented at the Biennial ISAAC Conference, the paper on this is provided in Appendix D.

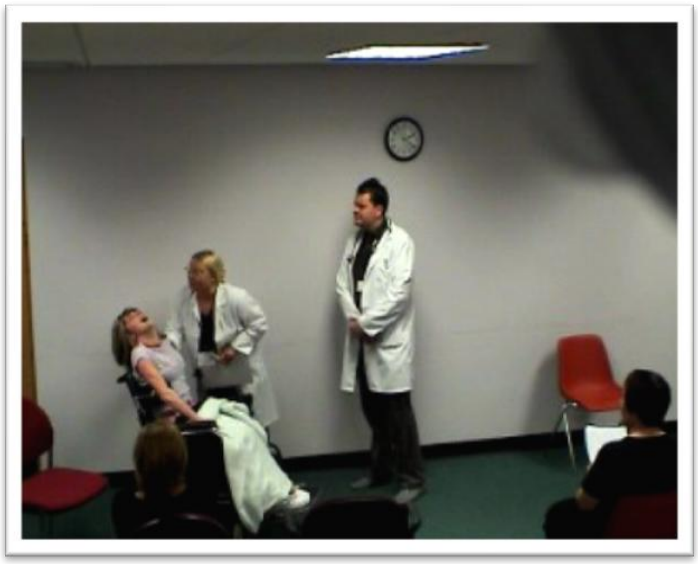


Figure 13 - Clip from First Play in Forum Theatre

6.7.2. Method

Following the creation of the video, a session was held with three participants to use the video in the gathering of requirements.

Figure 14 - Clip from Second Play in Forum Theatre

Three participants who had taken part in the focus group and were available to participate in requirements design decisions were invited to consider joining the group (see Table 5). The requirements gathering session took place in an activity room at the resource centre, with participants sitting around a table alongside the author and staff liaison from the centre.

Firstly the video was shown on a large television screen and paused at the tension point. The participants were invited to share their thoughts and at the end of the video a discussion was held thinking about what might have changed if the doctors had known more about the patient.

Table 5 - Demographics of Participants (Pseudonyms used)

Participant	**Method of AAC**	**Other Means of Communication**	**Established Group Membership**
Danni (29)	Lightwriter AAC Device	Vocalisation	Lives at resource centre
Robert (58)	Gestures	Dysarthric Speech	Attends resource centre three days a week
Doug (53)	Dynavox AAC Device	Dysarthric Speech	Attends resource centre four days a week

6.7.3. Potential for User Centred Design with Adults with SSPI

The use of forum theatre in the development of innovative technology is not new, however the literature does not report any previous work using adults with SSPI as actors in forum theatre or as participants (Prior et al., 2010).

The participants were able to follow the scenarios on the video, following the screening a short discussion was held on what they had seen. Robert felt he could empathise with the characters in the video "*I can relate to the situation*". Participants

became engaged in discussion surrounding the video, one example being how doctors would be able to see the information.

> **Doug**: See if they had the information when they started
>
> **Robert**: They need to have it at the start
>
> **Danni**: By my bed have it all the time
>
> **Doug**: I like that idea. Have it next to me, big flashing light saying pay attention.

Participants were also able to complete one of the tasks in traditional forum theatre, imagining alternative endings. By imagining the alternative endings the participants were able to then work through the steps that would have had to occur to reach this ending. At the end of this method the main stages in the information sharing process were outlined by participants for use in the next method.

6.7.4. Potential for Adapted Methods to Allow Adults with SSPI to be Participants

As stated previously the aim of this method was to understand the way participants would want to share information with medical professionals. The three participants identified four requirements of significance related to the information on the CHAMPION system. The first emerged as a direct result from the forum theatre video, participants wondered at what stage during their admission to hospital the medical staff would be aware they had information on the CHAMPION system and how this information could be conveyed to the admission staff.

Participants were also clear that one of their major concerns was that the doctors could see how they were when they were well. Doug related a story of a doctor

thinking his illness was affecting his arms as he was not able to carry out a request involving his left arm. Doug stated that he can never use his left arm and struggled to get a doctor to understand this.

The participants also felt that some information would be conveyed better by video than by text:

> **Danni**: I like writing
>
> **Doug**: sometimes it's quicker to watch a video
>
> **Robert**: Yeah it'd be good to have a mix of writing and video. Means we could choose.

The participants agreed that for some information e.g. toileting, a written summary of their needs would be best, but for other situations, particularly descriptions of how they act normally a video might be more appropriate. These requirements regarding the information were used in the development stages (see Section 6.11).

6.8 Storyboards with Adults with SSPI

At the end of the forum theatre session the main stages in the patient profile software information sharing process were outlined, these stages were turned into seven cartoons.

6.8.1. Methods

The cartoons showed a character creating information, logging onto the system, saving their information and then viewing it on the system. At no stage did the cartoon show the actual interface or how the cartoon user interacted with the computer (see Figure 16).

The participants were shown each frame and asked to think about what they would do on the computer at that stage:

Author shows frame 3

Author: So this scene is thinking about how the user will work with the computer and what equipment they use to do this. What sorts of extra equipment do you think you and other folk in the centre would need when working with a computer?

After each scene was shown and introduced, the participants would discuss the help they would need to complete the task, how they would expect the computer to respond and what they would expect to do at this stage.

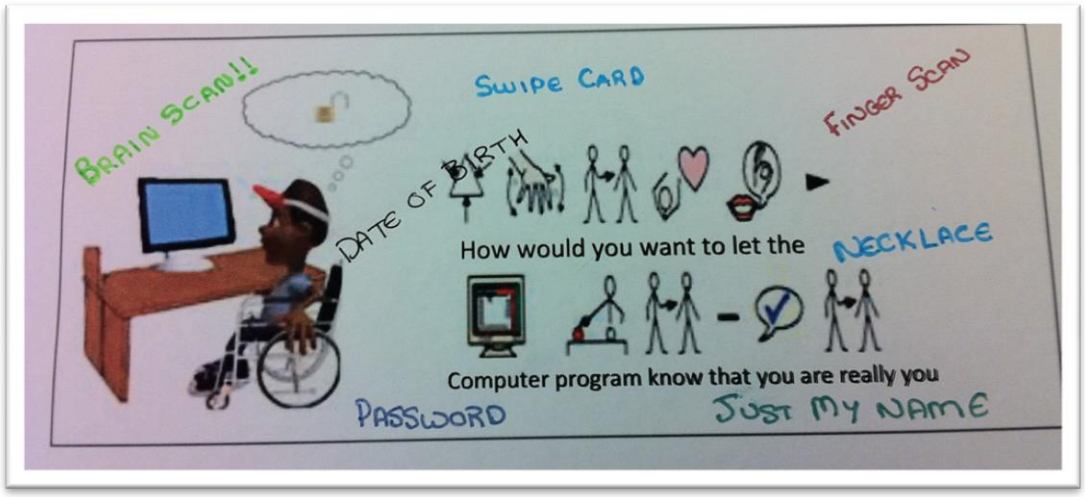


Figure 15 - Scene with Requirements Written On

Their ideas along with additional requirements were recorded on the scene paper. This allowed participants to have a visual representation of their ideas (see Figure 15).

6.8.2. Potential for User Centred Design with Adults with SSPI

The participants were initially reluctant in offering many suggestions, but after some encouragement where the author would address them directly or try to rephrase the question, the participants engaged in a lively discussion. Throughout the session participants showed the ability to compromise. An example of this can be seen when the participants were asked if they would prefer the information categories to be made for them or if they would prefer to make them themselves. Immediately Robert said he would prefer to make them himself

> "*a person like me, I know I'll take the easy option, but it's better to make me work it out"*.

Danni did not agree with this and felt she would need help with this. The question was asked again to Doug who could see the benefits and advantages of both but could not decide between them, Robert conceded that he could see that others like Danni "*need a lead to get you going"*. Doug replied wondering if the computer could make some guesses on what a user would need and suggested that users could answer a series of questions which would then provide the set of topics. This was welcomed by all participants.Participants were also able to show the ability to be imaginative in providing requirements, this can often be a problem when creating new technology (Carmichael et al., 2008). A good example of this ability is shown when participants were asked how they would want the system to know that it was them using the software and not an imposter.

> *Danni moves her finger up and down*
>
> **Author**: Do you mean you want to use your finger Danni?

Danni nods

Author: Like a finger swipe?

Danni nods

Doug: An eye scanner

Staff Facilitator: Ah you see our Doug is a sci-fi fan!

Doug (*laughing*): In my ear

Author: I'm not quite sure I understand Doug, can you tell me more?

Doug: Scan through my ear, put a probe in and check my head!

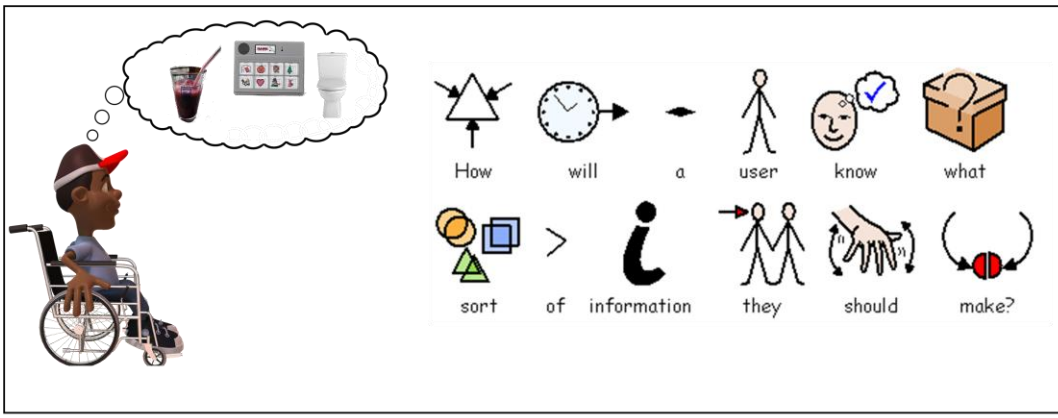
Robert: Yeah, but Doug this ain't Star Trek!

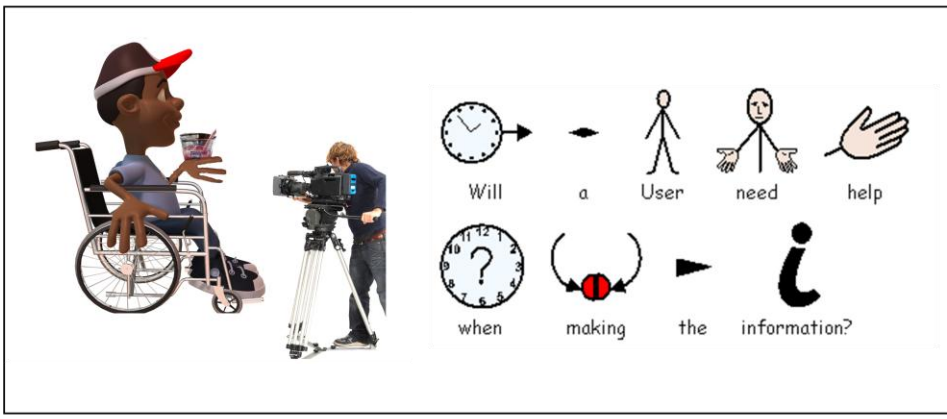
After this very imaginative suggestion the group appeared confident in thinking of other original ideas such as a key or a pendant that could plug into the computer. The group eventually all agreed that a barcode card or swipe card would be the best plan.

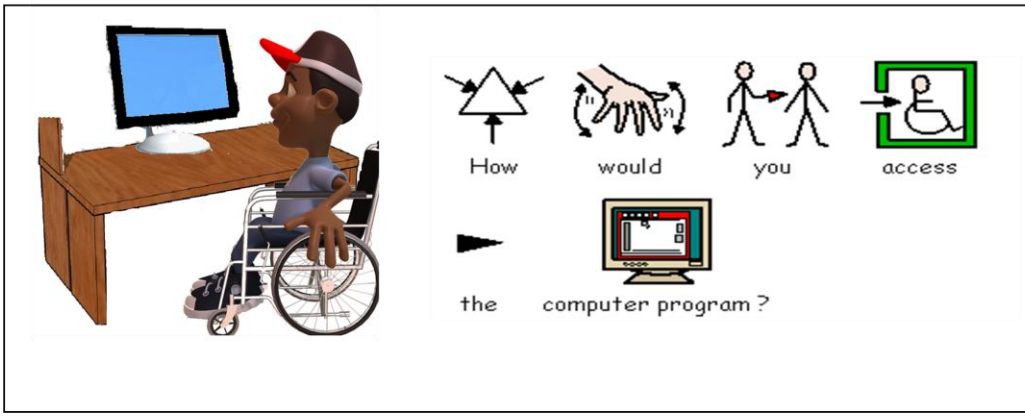
The participants showed they were able to understand the idea of imagining what the software might do and good at giving a list of detailed requirements. Participants could think of imaginative and creative solutions and also consider what others might like to see in the system:

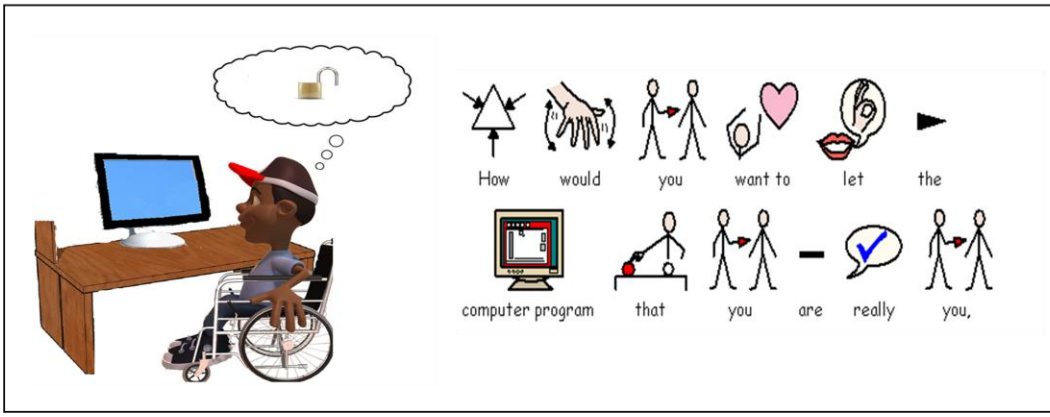
"I would be ok with that but other people might need help".

Differences of opinions were handled by the participants through discussions and compromises were reached.


How will a user know what
sort of information they should make?


Will a User need help
when making the information?


How would you access
the computer program ?


How would you want to let the
computer program that you are really you,

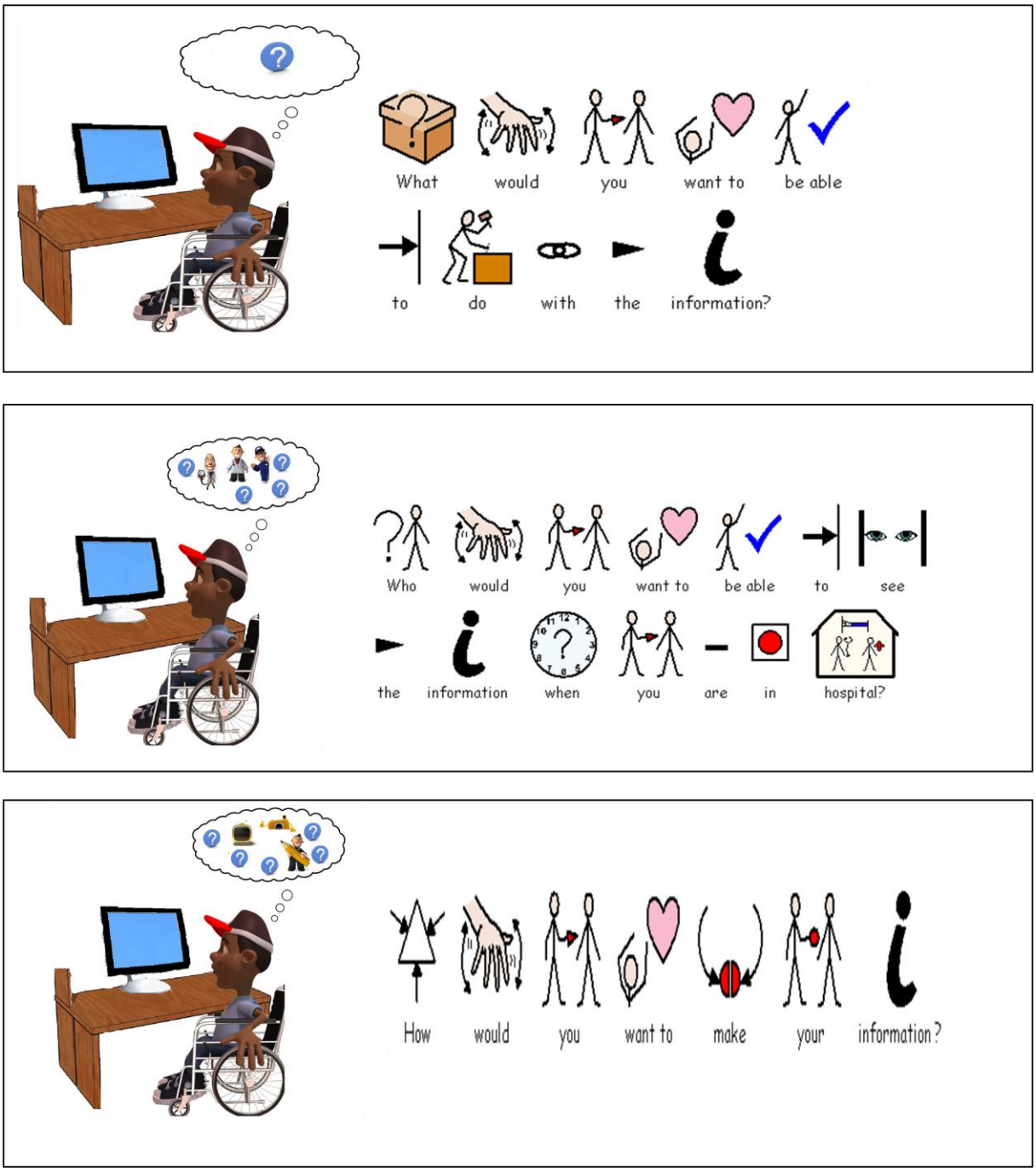


Figure 16 – Storyboard Featuring Scenes in Using System

6.8.3. Potential for Adapted Methods to Allow Adults with SSPI to be Participants

As a result of the storyboard session seven requirements emerged, all of these requirements came directly from participants. The first requirement was to have a questionnaire which would select the items of information that a user would be

prompted to provide. Participants stated that they would not find all of the categories of information useful and they would need some way of selecting the information items relevant to them. The questionnaire would appear when a user first registered with the system and users would be asked to repeat the questionnaire every six months to ensure the details were up to date. Participants were clear that the questionnaire should take as short a time as possible to complete.

The information was to be available in video, text or photograph form, a user would be able to use any combination of the information they wanted.

As stated previously one requirement which was the subject of a great deal of discussion was how a user would log onto the system. The requirement was that the user should be able to log in using an identity card with a barcode strip.

Participants requested the ability to look at, change and add information. It was also a requirement that no log should be made of the changes that had been made, participants were clear they did not want to have to look at the way their information had changed.

The software was required to be compatible with a variety of PC peripherals including mouse, switches and touch screen. The participants were clear that switch access was an essential requirement.

The final requirement emerging from this stage was that the user should be able to select which members of staff were allowed to see the information and that the staff should be sub divided into five categories: doctor, student doctor, nurse, student nurse, other staff.

6.9 Review of Requirements Gathering Stage

As stated, during the requirements gathering the main aim was to understand the needs of the end users, other stakeholders and the environment. As this form of software had not existed before, and the end users had traditionally been excluded from research, it was decided to use forum theatre as this has provide useful in similar situations. Storyboarding was seen to be a good complement to this method.

The forum theatre was based upon stories from the previous stage's focus group and depicted problems that can occur in hospitals when information is not shared appropriately. This then fed into the storyboard which presented an alternative ending to the theatre's story when the CHAMPION software was available. The storyboards showed each of the stages the end user would work through in creating their own patient profile. The participants provided a well structure list of requirements (see Appendix I) and this allowed the author to begin preparing for the next stage of producing design solutions to the problem.

6.10 Produce Design Solutions with Adults with SSPI

The production of a design solution will usually begin with a prototype (Hakim and Spitzer, 2000). Prototyping originated in mechanical engineering and design when a model of a new device would be created, often smaller than the final version and with poorer quality materials (Sharp et al., 2007). The aim of a prototype would often be to create a proof-of-concept and to evaluate the potential for the end device to work.

In the early 1990s there was an attempt to document how prototyping should be done in software engineering, and establish guidelines for this (Nielsen, 1992). Now

prototyping is an accepted process in software design and is included in the ISO standards for user centred design (ISO, 2010).

A full discussion on the types of prototyping is provided in Chapter Five.

6.11 Low Fidelity Prototyping with Adults with SSPI

There was an awareness that users unused to critiquing software could be reluctant to provide critical feedback and that they would need to be 'coached' in how to do this (Eisma et al., 2004). In order to assist with this it was decided that the prototypes should start with low-fidelity prototypes. Low-fidelity prototypes have very limited functionality and are typically produced using paper sketches (Rudd et al., 1996) (see Chapter Five).

By beginning in this way it was hoped that participants would gain confidence and experience in providing constructive criticism of the software by the time it reached the later more challenging stages.

6.11.1. Method

Paper prototypes are usually sketches by the designer or participants with which a participant can ‘press’ a paper button and then be shown what would happen from that (Rudd et al., 1996). The problem anticipated with using this method with participants with SSPI was that the participants would not be able to easily draw a sketch or reposition small paper items. Due to participants’ problems in fine motor control and visual impairments the author felt that the participants would need something more tactile and colourful to engage and to help with any sensory impairment.

The other requirement for the paper prototyping was that the objects in the process were large enough to be moved around on the prototype screen. Large pieces of foam were cut to shapes representing objects on the screen and magnets attached to the back of these in order to facilitate this (see Figure 17).

Figure 17 - Magnetic Paper Prototyping

This allowed the author to place objects on a screen sized magnetic white board and present the screen to participants at an angle in front of their wheelchair (see Figure 18).

Figure 18 - Participants Using Magnetic Prototypes

Participants were then asked questions such as "*How do you think you would let the computer know you wanted to save a picture for your information?*" or "*Can you show me how you would do that?*". These questions are used in traditional HCI and were aimed at uncovering how a user would be able to interact with a computer if the prototype was turned into a fully working piece of software.

6.11.2. Potential for User Centred Design with Adults with SSPI

Participants commented on what they liked and did not like about the screen and were encouraged to move the objects to positions that made more sense, ask for the text on the object to be reworded or to ask for the size of the object to be changed.

The participants reported enjoying this session and were able to offer negative and positive feedback, and suggest features that should be changed and features that should be added.

As in the previous session the participants showed the ability to compromise and think of creative solutions to problems. One new ability demonstrated by participants was that of helping each other. At one point Danni had stated that she did not like the text on the button (e.g. "Browse For File") and could not work out what it meant.

> **Robert**: I think it means you need to pick where the file is stored on your computer.
>
> **Danni**: I don't understand
>
> **Robert**: You know when you put something on a computer? That means it wants to know where it is
>
> **Danni**: Ok

Doug: It should say Find The File then!

Following the session in discussion with the author, the study co-ordinator highlighted this as the continuing personal development of participants. This move to help each other solve problems was new to all of the participants.

6.11.3. Potential for Adapted Methods to Allow Adults with SSPI to be Participants

The main issues were that although users might wish to use a touch screen, they were not all able to use a finger to point and used the side of their hand, this meant buttons, lists and text boxes all had to be bigger. It also showed that the text on buttons was often too technical in language, and that two of the participants would need the text read out to them. In this section, four changes were suggested (see

Table 6). These changes included two functional requirements (requirements related to how the software operated) and two design requirements (requirements related to how the software looked). All of the requirements came directly from participants.

The two functional requirements related to the accessibility of the software. When Doug was using the paper prototype he required the text to be read out to him, as although Doug had some literacy, his visual impairment meant he could not focus on the text. Doug realised this and asked the author if it was possible for a computer to read objects out to him in the same way. The requirement for voice synthesis was added to the list of requirements.

While the author was doing manual scanning by pointing to the objects, Robert commented that he had been trying eye gaze and he had enjoyed it. He put in a request for eye gaze in the system, stating that he thought it would help other users as well.

As stated previously Danni had struggled with the language used on one of the buttons, this was a common problem. Often technical terms such as “log on” or “browse for file” were used. Although the participants had used computers before, they were often assisted by a support worker when doing this. This meant that when more technical terms were used the support worker would carry out the task. The requirement for less technical terms was added.

The author had used pictures to aid the text on the buttons but it emerged that that participants would have preferred the addition of a symbolic language rather than general pictures. This requirement was to be implemented as soon as possible.

Table 6 – Alterations to Design from Paper Prototyping

Name of Requirement	Functional Requirement	Design Requirement	Suggested by Participant	Suggested By Author
Put in voice synthesis	*		*	
Use eye gaze	*		*	
Change wording on questions		*	*	
Have symbols on buttons		*	*	

6.12 Mid Fidelity Prototyping with Adults with SSPI

Mid fidelity allows software to have the appearance of a working program while still being easy to alter and rearrange without needing to code. It is used after the early initial design to look at detailed design and usability validation (Engelberg and Seffa, 2002).

6.12.1. Method

The main tool used in general design for mid fidelity prototyping is PowerPoint (Engelberg and Seffa, 2002)

With PowerPoint, designers can put in animation to give the impression of a task being conducted, this does not require programming skills (Hakim and Spitzer, 2000).

PowerPoint does have disadvantages; it is unable to support full interactivity (many tools are limited to hyper linking) and as these links are static the functionality is limited (Hakim and Spitzer, 2000).

When the author investigated the use of PowerPoint in this stage of the process for participants with SSPI, additional problems emerged. In PowerPoint including keyboard shortcuts is a very complex task, reducing the potential for incorporating switch access into the animation.

In PowerPoint the scanning would also have to be hardcoded in which requires considerable effort. It is also difficult to have voice synthesis for specific buttons.

In consultation with staff at the care centre and other assistive technology researchers it was suggested that the author could use Clicker5 (Cricksoft, 2011), a piece of software originally designed for use in education to help children with disabilities with reading and writing. It emerged that Clicker5 could be used for mid fidelity prototypes in a similar manner to PowerPoint. It has several accessibility advantages; it has a high contrast colour option (for those with visual impairment) and is fully switch accessible. It also has voice synthesis options and can read the text on objects in the Clicker5 screen when they become selected.

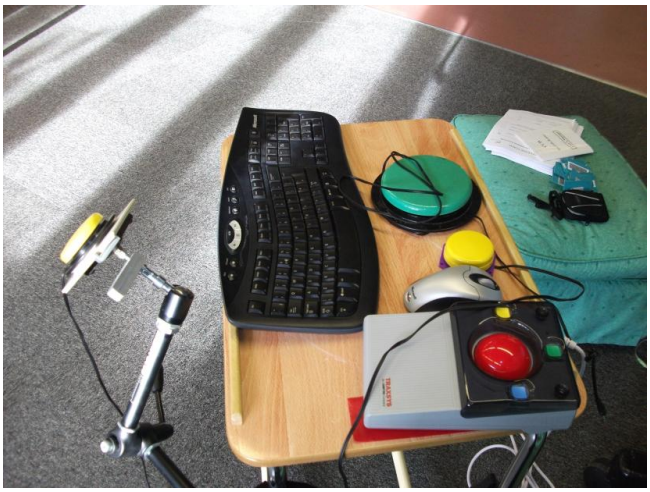


Figure 19 - Peripherals

The photographs from the lo-fidelity screen plans were used to guide and direct the design of the interactive mid-fidelity prototype.

For this design session the participants wanted to use their own preferred access methods (e.g. mouse, touch screen or switch). A large 37 inch touch screen monitor was set up with the options of keyboard and mouse, touch support or switches (see Figure 19). Due to these different access methods, three individual sessions were held when the participant had sole use of the system. A group session was held following these to discuss what they thought about designs.

6.12.2. Potential for User Centred Design with Adults with SSPI

In this method the participants demonstrated the ability to think more critically about designs and were able to describe in more detail why something did not work.

e.g. **Robert**: See this bit, it doesn't make sense

Author: Can you explain that a bit more?

Robert: Well see the button, when it just says quit I think that means quit this bit but the whole thing closes

As this example shows, participants were able to go into more detail about why they did not like certain aspects of the design, or what parts of the design were confusing them.

6.12.3. Potential for Adapted Methods to Allow Adults with SSPI to be Participants

This session revealed several issues simply by observing the participants and their use of the systems. Firstly, as Danni (the touch screen participant) had to use the side of her hand to select an object rather than her finger due to reduced dexterity, not only did the buttons need to be larger, they also needed to be placed away from the edges of the screen to prevent other windows being opened or closed (see Figure 20).

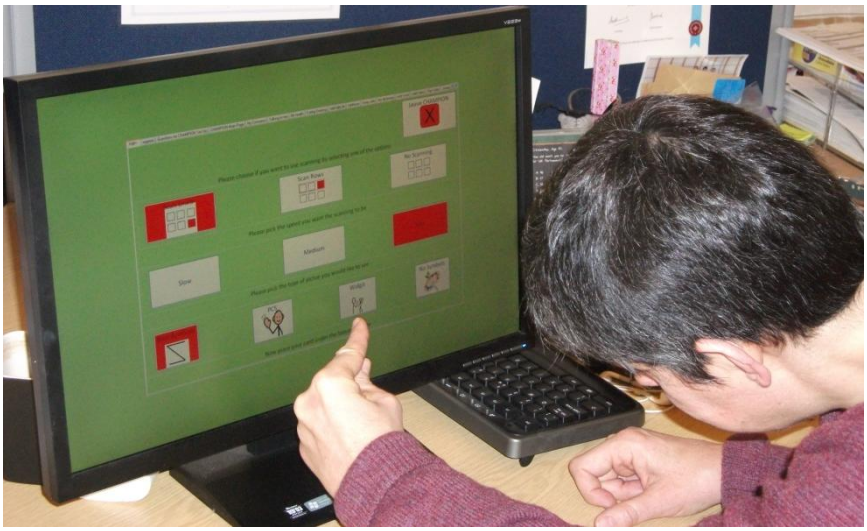


Figure 20 - Participant Using Mid Fidelity Prototype

The other issue observed was that it was necessary for the scanning to be switched on and off. The scanning was a distraction and was not required when the touch screen or mouse was being used.

In the discussions Doug, who used switch access requested that different "*types of scanning*" were used, previously only linear scanning had been available.

During the discussion participants confirmed the observation that they were able to cope with having the different types of information hidden behind category headings rather than having all information on the screen.

Table 7 - Alterations to Design from Mid Fidelity Session

Name of Requirement	**Functional Requirement**	**Design Requirement**	**Suggested by Participant**	**Suggested By Author**
Alter voice synthesis	*		*	
Get rid of back button in questionnaire	*			*
Just press yes/no to move through questions	*		*	
Use AAC device as keyboard	*		*	
Change wording on questions		*	*	
Stop it interfering with other buttons on screen		*		*
Make buttons large and centred		*		*
Have symbols on buttons		*	*	

Following this session, a further eight changes were made before moving onto a high level prototype. These changes included four design requirements and four functional requirements. Three of the functional requirements came directly from participants and two of the design requirements came from participants. The other requirements arose after observations by the author and were approved by the participants during

discussions. Details of the requirement changes and additions are contained in Table 7.

6.13 High Fidelity Prototypes First Iteration with Adults with SSPI

Following the "throwaway" mid-fidelity prototyping the next stage is usually the development of a evolutionary high level prototyping (Isensee and Rudd, 1996). High level prototypes will looked like a finished piece of software but will have less functionality (Rudd et al., 1996).

Marc Rettig (1994) argues that more projects should use the low-fidelity prototyping because high fidelity prototypes take too long to build and therefore developers are reluctant to change something they have worked so long on.

The CHAMPION project was careful to avoid the problems described by initially concentrating on the interface of the software. The software was run in Visual Studio[12] as this allowed for quick bug fixing. The software had limited functionality to begin with to help reduce the time required when changing features. Participants were encouraged to think about the ease of use as well as the appearance.

6.13.1. Method

The three participants from the prototyping sessions each had individual sessions lasting one hour using their preferred access method and then again came back together to discuss their views.

[12] Visual Studio is an Integrated Development Environment, a software application that allows software developers to program their own pieces of software.

6.13.2. Potential for User Centred Design with Adults with SSPI

This time it was clear that participants were more confident in giving their opinions in the feedback. Doug who previously had been the least forthcoming in his opinions was particularly notable as an example of improved confidence.

> Doug was set up with switch access in front of the screen and asked to explore the software. Doug was very adept at scanning and quickly moved through the different areas of the software. After two minutes he hit the exit button. The author and support worker assumed that he had selected this button by mistake and offered him the option to start again.
>
> Doug replied that he did not want to and when asked if he wanted to elaborate on this replied: "*it's easy to use, but it's for kids"*.
>
> The author probed this further and discovered that the reason Doug felt this way was due to the cartoon like graphics and "Comic Sans MS" font.
>
> The author then worked with Doug to look at other possible fonts and images which were later approved at the group design sessions.

6.13.3. Potential for Adapted Methods to Allow Adults with SSPI to be Participants

Other issues raised by participants included a dislike of the topic titles either being too complex e.g. "Mobility Assistance" (later replaced with "How I move"), or too direct e.g. "Toileting" (later replaced with "Personal Care").

By using Visual Studio to run the software, the alterations could be implemented instantly and the participants could then discuss if it makes the software better or worse. Doing this often revealed new problems that could occur as a result of the change so that solutions for the new problem could then be discussed (see Table 8).

Table 8 - Alterations to Design from High Fidelity Sessions First Iteration

Name of Requirement	Functional Requirement	Design Requirement	Suggested by Participant	Suggested By Author
Swap between symbols	*		*	
Change scanning speed	*		*	
Use less “cartoon” like drawings		*	*	
Allow changes on staff who can see information	*		*	
Make all buttons the same size and improve consistency in the software		*		*

Review of the First Iteration

Two problems with high level prototyping emerged in this iteration. The first immediate problem was the time taken at the start of each session to set up the different access options for participants. Connecting the device, configuring it for use with the system and testing the device took time away from the session with the participant and forced them to wait while this was sorted. It would have been useful to have set aside 20 minutes at the beginning of the day to ensure this was all working.

During this session it also became apparent that if the participants were tired it was best to abandon the session. On one day, two out of the three participants were tired so it was decided to rearrange for another day and participants were reassured that this was not a problem. One participant was feeling up to a general chat and this was an opportunity for a more relaxed conversation about the technology.

It is important to build extra time into a project plan to allow for this. It is already common to build time through risk management analysis into a project. This time should be increased when planning for work with people with SSPI. It is estimated that children with cerebral palsy (a major cause of SSPI (Larsson et al., 2009)) are 4.3 times more likely to be admitted to hospital as a result of illness while for adults the figure is 10.6 times than non-disabled peers (Young et al., 2007).

It also became clear that participants were not put off giving criticism of the designs despite a more "polished" appearance as shown by the previously described example with Doug.

6.14 High Fidelity Prototyping Second Iteration with Adults with SSPI

For the second iteration extra time was allocated to set up the different peripherals that the participants would use.

6.14.1. Method

Functionality was added to features in the software, which had already been approved in the first iteration. There was still limited functionality for the portions of the interface that had not been agreed on.

The participants made a few comments on the updated designs but were overall happy with the software. At this point it was decided to bring a fourth participant (Gavin) into the project (see Table 9).

Gavin had been aware of the project from the beginning but had been unable to participate due to conflicting commitments. When the original three participants felt they would like a second opinion on their choices it seemed an obvious choice to ask Gavin to join.

Table 9 - Demographics For Gavin

Participant	Method of Communication	Computer Access Method	Established Group Membership
Gavin (32)	AAC Device	Touch Screen Wobble Stick	Attends resource centre four days a week

6.14.2. Potential for User Centred Design with Adults with SSPI

During this stage the participants became aware of the fact that there was little they were able to suggest to improve the design of the software. It was the participants who recognised that this might be due to their experience with the system and they suggested recruiting a new participant to assist.

6.14.3. Potential for Adapted Methods to Allow Adults with SSPI to be Participants

Gavin was on the whole pleased with the designs but did request more instructions for signing up and changing information. The other participants had not noticed this lack of information as it related to features they had seen throughout the different iterations (see Table 10).

6.14.4. Review of High Fidelity Prototyping

Following this session participants discussed how they could involve more people from the care centre in the evaluation of the software. Robert suggested setting up the large computer in the social area of the centre and having the software running. He felt the other members of the centre were "*nosey so and so*" and would likely come over to see what was happening. Danni added that they could have a poster up so people knew what it was. The participants offered to organise this event with the agreement that the author would set up the technology on the agreed date.

Table 10 - Alterations to Design from High Fidelity Sessions Second Iteration

Name of Requirement	Functional Requirement	Design Requirement	Suggested by Participant	Suggested By Author
Change voice synthesiser used	*		*	
Change wording on some buttons		*	*	
Allow user to choose whether instructions should be read out	*		*	
Provide Information on Registration		*	*	

6.14.5. Review of Prototyping

The producing of design solutions aimed to involve the end users in developing a design solution from basic low fidelity prototypes into a high level functioning prototype. Many of the traditional methods used in prototyping were not suitable for this user group and so adaptations had to be created. The adapted methods included magnetic foam prototypes and Clicker5 interactive prototypes. While using Visual Studio for high level prototyping is not new (Rudd et al., 1996), additional care had to be taken to make sure the sessions were not too complex for the user group.

This stage showed that the participants were able to progress from low to high level prototypes and could provide detailed feedback and constructive criticism at all levels. Towards the end of this stage a new participant joined the group to provide a fresh outlook. The participants agreed to help organise the final evaluation stage with new participants.

6.15 Software Evaluation with Adults with SSPI

The aim of evaluation is to collect information about the user's experience when working with the software (Boehm et al., 1976).

The evaluations were to make use of semi structured interviews, observation and diaries. All of these methods would be used while the participants were carrying out tasks of their own choosing on the system.

6.15.1. Method

By this stage in the development the author was firmly ingrained into the environment of the centre and was able to work in it without being a major distraction to staff, this was evidenced in her participation in activity sessions. Participant-as-Observer observation would allow the author to watch the new participants using the software for an initial three days before leaving them with the diaries for a longer term evaluation (see Chapter Five).

Figure 21 - Poster For CHAMPION Evaluation

The staff at the centre arranged for posters (see Figure 21) to be placed in the main meeting room around the large touch screen monitor.

A wide range of different peripherals (including switches and joysticks) were set up with the computer so that participants could come up and use the device in their own time. A user guide on how to load the software, extra participant information and consent forms were left by the monitor as well.

Four new participants (see Table 11) were taken through the informed consent process and were given an introduction to the project and provided with their own log in cards. Each participant spent half an hour with the author setting up their account and exploring the software. The author gave minimal instructions (e.g. “Can you try and add some information about how you eat?)” and only gave assistance when requested. All requests for assistance were noted for inclusion in a user guide for the final version.

During these initial sessions, tasks carried out on the software were limited. Participants were provided with a set of tasks to carry out in the longitudinal study. Participants were also shown how to complete the diaries during the longitudinal phase (see Appendix J). After the initial session each participant was interviewed individually on their initial impressions of CHAMPION. This was aimed at discovering its initial usability and questions centred on how easily participants felt they would manage on their own and problems they anticipated in using the system.

6.15.2. Potential for User Centred Design with Adults with SSPI

Midway through the evaluation period the staff at the centre were having difficulty in accessing the software. They contacted the author to ask for advice and the author attempted to rectify this by taking remote control of the software. However, the

computer did not appear to be capable of connecting to the internet. The author then went to visit the centre to try and solve the problem. On arrival it was apparent that the internet was not working. None of the staff knew where the modem was situated and a search took place to locate it. Once it was located, the problem was identified easily as the modem had been unplugged. Once this was corrected, a second briefing session was held for staff.

Table 11 - Participants in Software Evaluation

Participant	**Method of Communication**	**Computer Access Method**	**Established Group Membership**
Paul (21)	Eye Gaze	Eye blink glasses	Attends resource centre four days a week
Patricia (44)	Signing, Dysarthric Speech	Switch	Attends resource centre five days a week
Lisa (40)	Facial Gestures, Dysarthic Speech	Switch	Attends resource centre four days a week
George (35)	Dysarthic Speech, Word Board	Switch, Keyboard	Attends resource centre two days a week

At the end of the two months the author returned. Only limited sessions had been held as participants had experienced problems in finding uninterrupted space to use the system. Staff had also experienced difficulties in finding free time in their busy schedules to assist or encourage participants to use the software.

The diaries had only been used once and so the planned semi structured interviews were not possible. A short discussion was held with participants based on the limited sessions that had occurred. Participants stated that they enjoyed using the system and would like to use it again.

6.15.3. Potential for Adapted Methods to Allow Adults with SSPI to be Participants

Four short term evaluations were conducted by the author during this two days. The results were very positive, participants pointed out three minor problems related to the layout of the program. A discussion was held related to these issues and changes were made.

Following the three recruitment days and with four new participants recruited the system was left at the centre for two months along with a diary for staff to write in with participants. This was less successful and suggests that having a researcher onsite at regular intervals during the evaluation period would be beneficial.

6.15.4. Review of Software Evaluation Process

The evaluation stage was divided into two sections, firstly a short term evaluation designed to recruit new participants and get their immediate feedback. This took place over three days at the care centre and recruited three new participants who conducted usability evaluations and were able to provide feedback, despite the fact that they had not been trained in evaluations as the original participants had. A longer evaluation session was then attempted but due to problems at the centre and the equipment there, limited sessions had been conducted. Despite this the short term evaluation demonstrated that participants with SSPI could quickly take part in usability evaluations with limited training. Four participants were able to complete tasks such as adding information, looking at information and changing information. These tasks were completed fully by participants who had only had thirty minutes initial training.

6.16 Evaluation of Participant's Experience of Process

6.16.1. Participants' Views of Process

Following the conclusion of the evaluation process Danni, Doug and Robert (the original three participants) and the staff liaison met with the author to look back over their experience of being involved in the project.

The participants were asked eight questions and the answers recorded by the staff member on an A1 sized flip chart using graphic note taking to help engage participants in the process (see Figure 22).

Author: What did you think about being involved in making CHAMPION?

Doug: It's the way you should do it

Robert nods energetically

Robert: "if we can see the goal of the project its worth doing",

Danni indicates she wishes to speak

Danni: I have enjoyed all of it

Author: Anything else you want to say about it? Ok so what was your favourite part of the project?

Danni: Designing stuff was really good

Doug: Drama was best

Author: Anything else?

Doug: being listened to

The questions had been read by other researchers ahead of the session to ensure they were not leading.

This discussion had provided some interesting answers. Danni who had previously only shown an interest in drama at the centre had enjoyed designing more than doing drama while Doug who usually did not enjoy being the focus of attention had enjoyed the drama most. Poignantly Doug also said that the thing he had enjoyed the most was being listened to.

This was a theme that had previously been seen in the focus group sessions (see Section 6.5).

Participants were encouraged to think about the negative parts of the process and were told that this information would be useful and help make the process better next time. The participants said that they could not think of any negative aspects. This could have been because they did not wish to upset the author but in the past the participants had been keen to provide negative feedback. The question was then rephrased to ask them if there was anything they would like to have done differently, Doug would have preferred a different room and Robert would have liked to have been able to work in an area with fewer interruptions and had more access to different types of equipment.

Figure 22 - Graphic Review of Participant Debrief

The discussion then turned to how participants felt when taking part in the research (see Figure 23).

Author: Now, thinking back over everything. I wonder how you guys have felt while doing the project?

Danni: Active

Author: Can you tell me more about that?

Danni: I liked being active

Robert: It's about inclusion. Inclusion is what we want.

Doug nods

Doug: It felt good. Being involved.

Figure 23 - Feelings when Taking Part

The author then asked the participants to sum up the project in three words or less (see Figure 24), they replied with "*inclusion*", "*possibility*" and "*it's the best*". The discussion ended with participants being asked if there was anything else to note and Doug replied with "*what we do matters*".

The use of focus groups with these participants had already been shown to be effective in getting useful insights and new information. This focus group was of a different form to previous sessions, it was more relaxed and participants were being asked to undertake personal reflection as opposed to relating stories from past events (see Section 6.5) or evaluating technology (see Section 6.15).

Figure 24 - Summary of Project

There was a danger that participants may have forgotten aspects of the process or were only remembering the positive aspects and had forgotten negative aspects This was mediated to some extent by the author going through all the stages one by one to ask participants' opinions. By having a group interview as opposed to individual interviews, participants were able to remind each other of things they had forgotten. The group discussion itself does create problems to validity in that participants may have been reluctant to reveal stages they did not like for fear of how they would be viewed by the other participants. This was not felt to be a significant problem, over the course of the work on the project the participants had bonded and had become comfortable in discussing tasks they could not do with each other and expressing personal opinions confidently.

The final risk of the credibility of this session is that participants would be uncomfortable in relating to the author any aspects they had not enjoyed of the process. Through the process the author had become regarded as a member of the group and the participants may have been wary of offending her. In order to minimise this risk the author attempted to portray the analysis of the process in the same way that the analysis of the prototypes and software had been conducted. Participants were informed that by revealing negative aspects they would be assisting in making the process better, had there been any major negative aspects of the study the participants by this stage would probably have had the confidence to reveal this to the author.

Following the debrief with the participants a separate interview was held with the staff liaison, she also reflected positively on the experience of being involved and offered further insight into changes observed by staff on the participants' confidence and behaviour since the start of the study.

Robert had always been the most confidant and outspoken of the group and had the least change noted. The only difference that the staff had observed was that he no longer sat alone at lunch because Doug now always insisted on eating with him.

Danni had also previously shown some confidence but this had been noticed as increasing. The other major difference seen was that she was now expressing an interest in doing more projects and getting into possible employment.

The person who had shown the greatest change was Doug who previously had been very isolated and reluctant to enter into conversations with people outside of his immediate social circle. Since taking part in the project he had joined the drama

group, was using his AAC device more and was voicing his opinions with staff when they did something he was unhappy with.

These observations would appear to suggest that not only did participants give a large contribution to the design and functionality of the software, the experience was positive for the participants as well.

6.17 Credibility of study

The main danger to the credibility of this portion of the study was the analysis of whether adults with SSPI could take an active role in user centred design. There was a risk that the author would unintentionally make the decisions on the software design or requirements but attribute them to the participants, or provide the answer to questions she had asked and then only ask participants if they agreed. This would make it appear that the participants were able to provide requirements and make decisions on design when they actually had not done this.

The author was conscious of this and did her best to minimise this. At regular intervals the author checked with participants that they meant what the interpretation was. In addition the researcher was careful not to provide suggestions immediately, only if the participants could not think of any solution. All of the sessions with participants were video recorded and these videos were viewed by a second researcher who agreed that this had not occurred.

The sample size was small, under Nielsen's usability guidelines (1993) there were enough participants to evaluate the usability of the study. However, to investigate if people with SSPI can conduct User Centred Design a larger sample size is required and in different centres. Restricting the study to one centre opens it up to the risk that

the staff in the centre or the type of participants who chose to use that particular centre could be confounding the result.

There was the risk that the group of participants did not constitute a true reflection of the SSPI population. As far as possible representative sampling was conducted, the final four participants covered the age range of 25-65 (mean=43.75, median = 42.5). Unfortunately it was not possible to get a balanced male to female ratio (3:1). This was due to the fact there were fewer females at the centre who used AAC devices and only the one (Danni) who was available to take part in the sessions and who was able to provide informed consent (the two other females from Section 6.5 were no longer available as participants when the requirements stage began). Despite this it was felt that the sample was representative. The participants had varied home environments: living with family, living in supported accommodation and living in care centres. They also had a variety of educational experience and used a variety of communication aids.

6.18 Limitations to Study

It would have been useful if more methods could have been trialled but it is not clear if this would have uncovered more information from users. It would not be ethical to 'waste' their time using more methods to get the same information back. It is also not clear if this would have been a useful way to evaluate the potential for methods as after the first method in a process the participants could lose motivation or not provide information as they would feel it to be the same as the previous method.

The study could have been improved by conducting two concurrent software development projects with two groups of participants to compare the differences between the groups and to ensure that the one group of participants were not an

isolated event. This would have proved difficult due to the extra time this would have required and the extra resources needed.

Given the ways the study could have been improved it was felt that a second study was needed to address the concerns that the results may have been due to the participants and to explore different methods for the stages of the User Centred Design process. This second study would be conducted with a new group of participants from a different centre to ensure that the participants were not a special case and that more people with SSPI could take part in User Centred Design. It was also decided to use a new developer to ensure that this was not a confounding variable.

A set of guidelines were produced (see Chapter Seven) following the CHAMPION study, these were then provided to a second developer in a new software project with adults with SSPI (see Chapter Eight).

6.19 Summary

The CHAMPION study demonstrated that adults with SSPI were able to be actively involved in the development of software. The author learnt many lessons in this project and it was felt that these lessons could be of benefit to others. The lessons were developed into guidelines and these are discussed in Chapter Seven.

Chapter 7. **Development of Guidelines**

"This is the way you should do it".

Robert, a participant in the study with SSPI

7.1 Introduction

Chapter Six demonstrated the ability of adults with Severe Speech and Physical Impairments (SSPI) to take part in software development tasks. Given the lack of guidance available for developers wishing to work with this group in design, the author made the decision to produce a set of guidelines based upon lessons learnt in Chapter Six.

The way in which the guidelines were collated along with an overview of the guidelines are presented in this chapter.

7.2 Development of Guidelines

Following the completion of the CHAMPION development an analysis was conducted to investigate what lessons had been learnt and if these could be of benefit to other developers. This analysis involved a triangulation of data from video tapes, transcripts and an examination of features in the software.

7.2.1. Video Tape Analysis

All of the sessions with participants had been video recorded, with the exception of the debrief at the end of the project. These videotapes were reviewed by the author, the tapes were analysed for moments in which one of the challenges in the literature had been addressed. Every time a challenge was addressed it was noted, at the end of the analysis all of the notes were examined together to identify what challenges had been addressed and how they had been addressed. The problems that occurred in the

different sessions were noted during the watching of the videos and the author analysed why these problems occurred and what if anything could have been done to prevent them.

An independent researcher was asked to watch two hours of randomly selected videos to provide quality control. Ideally all of the video tapes would have been validated by a second researcher but due to time constraints this was not possible.

7.2.2. Transcript Analysis

Transcripts were prepared for every session and these were analysed for contributions to the software and for themes using thematic coding. This analysis was focused on both development in the participant's ability to take part in User Centred Design and in the contributions provided to features and requirements in the software. These were again verified by an independent researcher.

7.2.3. Feature Analysis

The final piece of triangulation analysis was the investigation into the origins of features and requirements. The features and requirements in the software which had been provided by participants were traced back to the session in which they originated. The reasons for the success in achieving this information were then analysed.

7.3 Preparation of Guidelines

Using this triangulation of data, the key areas were brought together and used to inform a new set of guidelines. Due to the popularity of the ISO guidelines in User Centred Design the guidelines for working with adults with Severe Speech and Physical Impairments were based upon these. The new guidelines are not intended to be used in isolation for mainstream development and should be used alongside

current guidelines on User Centred Design. The guidelines are presented below but are also available as an independent document in Appendix L of this thesis.

7.4 Guidelines for Working With Adults with SSPI in User Centred Development

7.4.1. Introduction

User Centred Design is an approach of interactive system development that focuses specifically on making systems usable. It is a multi-disciplinary activity which incorporates human factors and ergonomics knowledge and techniques. The application of human-factors and ergonomics to interactive systems design enhances effectiveness and efficiency, improves human working conditions, and counteracts possible adverse effects of use on human health, safety and performance. Applying ergonomics to the design of systems involves taking account of human capabilities, skills limitations and needs.

A person with Severe Speech and Physical Impairments (SSPI) will have different problems than a person with a Communication impairment which describes a disability affecting speech and language. A person with a communication impairment may have difficulties including articulation problems, fluency problems, aphasia and delays in speech (Medline Plus, 2009). SSPI encompass more than a communication disorder and include a range of physical, sensory and cognitive impairments (Balandin, 2002).

7.4.2. Working with adults with Severe Speech and Physical Impairments in User Centred Design

This standard provides guidance on conducting User Centred Design with users with Severe Speech and Physical Impairments throughout the lifecycle of the

development of a technology. This technology is not limited to assistive technology and could be a piece of technology for mainstream consumption. This standard is concerned with both hardware and software components of interactive systems.

This standard addresses the planning and management of User Centred Design with users with SSPI. It is based upon the guidance in ISO-9241-210 regarding conducting User Centred Design and as such does not address the specifics of the stage of the lifecycle specified in ISO-9241-210 but instead provides guidance on how these stages can be conducted with users with SSPI.

The main users of this standard will be those developers or researchers who will be working directly with users with SSPI. However it is beneficial for the entire development team to be aware of the issues in working with these users and how the project is addressing the issues.

7.4.3. Terms and definitions

For the purposes of this standard, the following terms and definitions apply.

a) Prototype

Representation of all or part of a product or system that, although limited in some way, can be used for evaluation [ISO 9241-210:2010, definition 2.2]

b) Usability

Extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use. [ISO 9241-210:2010, definition 2.3]

c) Effectiveness

Accuracy and completeness with which users achieve specified goals. [ISO 9241-11:1998, definition 3.2]

d) Efficiency

Resources expended in relation to the accuracy and completeness with which users achieve goals. [ISO 9241-11:1998, definition 3.3]

e) Satisfaction

Freedom from discomfort, and positive attitudes to the use of the project [ISO 9241-11:1998, definition 3.4]

f) User

Individual interacting with the system.[ISO 9241-10:1996, definition 2.2]

g) SSPI

Severe Speech and Physical Impairments encompass more than a communication disorder and include a range of physical, sensory and cognitive impairments (Balandin, 2002).

f) AAC

The general term for the methods used to aid communication by those for whom the more usual forms of communication are not sufficient. AAC can be divided into two different categories of unaided and

aided. Most people who use AAC will use a combination of the two (American Speech-Language-Hearing Association, 2002).

g) Support Worker

This refers to any person who assists the user in their day to day lives or in using the system. This may be a person employed to assist the user or a family member.

h) Developer

This refers to the HCI practitioner, the software developer or the researcher who is involved in the project.

7.4.4. Rationale for working with users with SSPI

The number of computer users with cognitive and developmental disabilities is increasing. Examples of this include: day and residential units holding computer courses as part of the program for service users (Parsons et al., 2006) and schools for children with disabilities now have ICT lessons in their basic curriculum (Judge, 2001). In addition, as adults with developmental disabilities become more integrated into the workplace, the demand for computer software which is accessible by a wider spectrum of users is likely to increase.

However, the main use of technology by this user group remains in assistive technology and AAC devices. As with other user groups, a lack of User Centred Design may contribute to the poor adoption of technology (e.g., the rate of abandonment of AAC devices is reported to be as high as 53.3% (Riemer-Reiss and Wacker, 2000)). The main reasons given for abandonment

or rejection of assistive technology are a lack of training for the end user and a lack of flexibility in adapting the system for the individual. Other reasons reported include a lack of confidence on the part of the user in their ability to use the system and the prohibitive costs in learning how to use the system.

It is suggested that the inclusion of end users in the design process may reduce this abandonment rate (Waller et al., 2005b)**.**

7.4.5. Structure of this standard

- Clause 5 outlines the problems that can occur with Severe Speech and Physical Impairments.
- Clause 6 gives an overview of the technology that are used to assist people with SSPI.
- Clause 7 discusses the problems that are noted when doing User Centred Design with users with SSPI.
- Clause 8 gives guidance on how to deal with these problems.
- Clause 9 highlights methods known to work at each stage of ISO 9241-210 with users with SSPI.

Clause 5 - Problems for people with SSPI

People with SSPI may have cognitive impairment which can range from mild to severe and may have difficulty in understanding all that is being said in the conversation and the developer's questions.

People who use an AAC device for communication can produce words up to 25 times slower than those with normal verbal speech (Higginbotham et al., 2008b). The time therefore for a participant to reply, for example "Yes, that has happened to me" could take up to 2 minutes for a participant relying on

AAC (Augmentative and Alternative Communication at the University of Washington, 2009). A person with dsyarthric speech may be able to produce words at the same rate as a participant without a SSPI, however the need for clarification of the response can slow down the rate at which the response is understood by the group (Hustad, 2006a).

People with SSPI are likely to become tired more quickly than the general population (Jahnsen et al., 2003a). This is attributed to "post-impairment syndrome", which means that those with SSPI will use between 3 and 5 times as much energy as those without the condition (Wood et al., 2008). Fatigue is also one of the most common and debilitating symptoms associated with Traumatic Brain Injury.

Clause 6 - Technology to assist people with SSPI

Augmentative and Alternative Communication (AAC) is the general term for the methods used to aid communication by those for whom the usual form of communication through speech is not sufficient. AAC can be divided into the two different categories of unaided and aided. Most people who use AAC will use a combination of both (American Speech-Language-Hearing Association, 2002).

In unaided AAC systems additional equipment is not used, for example sign language, Makaton (Communication Matters, 2008) and facial expressions (Communication Matters, 2003). These systems have the benefit that they can be used anywhere and the user does not need to carry additional equipment around. However unaided AAC has the disadvantage that the communication partner needs to understand how the system works.

Aided AAC systems refer to a communication methods that involve a device – this may be electronic or paper based (e.g. a word board) – of some form which is external to the user. The device can be used to transmit or to receive messages and generally display symbols which the user selects to convey messages to listeners, for example a symbol board (Beukelman and Mirenda, 1992). A user can select a symbol, picture or in the case of literate users a selection of letters to build up a message. The main advantage of an aided device is its ability to offer potential for communication to people with SSPI for whom unaided systems require refined motor skills or cognitive load not within the user's capability (Hampson, 2006). Electronic devices also offer the potential for synthesised speech output in the case of speech generating devices.

Other assistive technology for this group may include electric scooters or wheelchairs to assist with mobility, personal organisers or reminders to assist with cognitive difficulties, screen readers, magnifiers and hearing aids to help with sensory problems and environmental controls to help them to live as independently as possible.

Clause 7 - Problems that can occur when doing User Centred Design with users with SSPI

a) Can a group of 'representative users' be gathered?
    - gathering a representative sample of different disabilities and needs is more challenging

b) How can different accessibility needs be met?

c) Can informed consent be gathered from participants, and if not is it possible to gain assent from the participant and informed consent from a legal guardian.

- It is important to ensure that participants are aware of what they are consenting to
- Some participants may have a guardian appointed who is required legally to consent to research.

d) How will you encourage participants to give feedback?

- Participants are often uncomfortable in giving negative feedback to those who have designed the software

e) How will feedback be recorded?

- Usual methods such as notes and audio recordings may not be suitable
- Audio recordings may miss information if communication is not through a voice output machine
- It is difficult to take notes if participants are communicating via eyegaze and word board

f) Is it necessary to provide incentives to participants?

Payments can interfere with benefit rules

g) What measures will be put in place after the study to allow participants to continue with new skills if they wish to?

- Participants may have developed new skills during their involvement with the research and may be keen to continue with this after the project ends.

While organising future support is not the responsibility of researcher or developer, there is an ethical obligation to ensure that participants do not feel abandoned at the end of the study.

h) How will you report back to participants on what you used their feedback for?

- The traditional methods for reporting back to participants is by writing a letter to participants thanking them for their help and explaining what stage the project is now at. This may not be suitable for users with SSPI.

i) How will contact be made with participants?

- Recruiting end users can be a challenge in any situation, unlike traditional development advertising in local press or through local universities can be inappropriate or unlikely to reach the desired participants.

Clause 8 - Guidance on issues for User Centred Design and users with SSPI

a) Can a group of ‘representative users’ be gathered?

- It is not difficult to gather a spectrum of different ages and a mix of genders among participants but gathering a representative sample of different disabilities and needs is more challenging.
- It may be possible to use purposive or judgemental sampling to find users who cover most of main disabilities (communication impairment, mobility impairment, cognitive impairment and sensory impairment).

- Developers can encourage users to consider how others whom they know with different disabilities would interact with the system.
- Participants can be asked to consider talking to others about the system or to even ask them if they wish to take part in later evaluations.
- By allowing different groups of participants to do later evaluations it is possible to gain as wide a range as possible.

b) How can different accessibility needs be met
    - Conflicting requirements are already part of the user centred design process, in this situation however discussions between users and designers is unlikely to help resolve the issue.
    - The designers need to carefully examine the possibilities for including as many accessibility and adaptations as possible.
    - It may be possible to switch accessibility options on and off
    - Careful planning during development can often allow different adaptations to be used through the same piece of code.

c) Can informed consent be gathered from participants, and if not is it possible to gain assent from the participant and informed consent from a legal guardian?
    - By talking to participants after going through Participant Information Sheet and asking yes/no questions we can check that they understand what they are agreeing to.
    - It is still important to gain assent from the participants in the instance of a guardian signing. This should include questions to ensure they want to take part and know what will be happening in the process.

d) How will you encourage participants to give feedback?
    - Participants need to be encouraged to give negative feedback.
    - It is helpful to remind participants that you really want them to find flaws in the technology.

e) How will feedback be recorded?
    - Video can be intrusive, but careful planning can minimise this

f) Is it necessary to provide incentives to participants?
    - Methods of incentives can be through gift tokens etc, which should not interfere with benefit rules.
    - Participants will often volunteer to work without payment due to the enjoyment of taking part.

g) What measures will be put in place after the study to allow participants to continue with new skills if they wish to?
    - If it is possible for participants to take part in other projects then putting them in contact with the person organising these should be discussed
    - Researchers should discuss with the participants and their support staff what parts of the project they enjoyed most

h) How will you report back to participants on what you used their feedback for?
    - With participants with SSPI it is beneficial for them to meet with the development team and be given personal feedback on how the project has developed and how their own contributions have been used.

i) How will contact be made with participants?

- Charities who work with people with SSPI may be willing to make the initial contact on behalf of the development team and then if participants are in agreement to put the two parties in contact.
- There may be additional ethics procedures to go through with a charity and time should be allowed for this.

Clause 9 - Example methods for stages in User Centred Design

General Points

At the beginning of each session review the previous session, this will help any participants who were not present to be caught up on what has happened and will help participants with cognitive problems to recall what took place.

It is important to ensure that participants do not become overtired during the sessions, and to allow for extra time to facilitate breaks. Designers should remember that participants with SSPI are more likely to have illnesses than the general population and there may be times when sessions have to be cancelled or altered at short notice due to illness.

While it is important not to talk in an overly complicated or technical way with participants it is also vital that participants are not spoken to in a condescending tone and are made to feel as equals with the designer.

Understand and specify the context of use

Make contact with potential users and/or organisations who work with people with SSPI. It is important that participants become comfortable with the

researcher/developer prior to the work commencing. The staff or family who spend time with participants should also meet with the researcher/developer.

Examine the ethical situation carefully, in addition to any internal ethics procedures, there may be ethics applications required by the charities or organisations involved. The local health authority may also require an ethics application depending where the sessions with the participants will be conducted and how participants will be recruited.

Spend time in the environment and understand how the technology may be used.

Requirements Gathering

Requirements for how technology could be used

Adults with SSPI may at first be hesitant in giving requirements to researchers due to previous poor experience of having people in authority/people from outside of their immediate circle listening to them. As such a group discussion for requirements may be beneficial – particularly if it can be arranged for the participants to know one another before hand. During group discussions it is important for people to have time to form answers using their communication device and not to feel rushed into answering. Participants will benefit from being given feedback on what was discussed at the end of the session in addition to the traditional summary which is sent out a later date. By feeding back immediately on what the researchers have heard, participants will know that their opinions have been listened to and taken onboard.

Requirements on how technology should operate

Participants may have trouble imagining how technology will work or trouble keeping track of what part of the process in using the technology they are currently imagining. Providing storyboards or videos on problems that currently exist and/or how the technology could possibly be used may help alleviate this. It is important not to specify exactly what the system will do, but allows participants to visualise and imagine more easily. The research/designer can show on the screen an image of the position of the process that is currently being discussed. It may be helpful to prompt for consideration of other groups.

Produce Design Solutions

Lo-fidelity prototyping can involve producing sketches of how technology will look and/or in User Centred Design having the participants produce sketches for how they imagine the system looking. This is not usually a suitable method of prototyping with adults with SSPI. One technique found to be successful is to create more tangible prototypes. Examples of this include making models of the device onto which components can be attached on as the participants wish, or by creating screen designs and then cutting up the buttons etc. These components can then be attached to magnets, the participants can then position the components on a magnetic board in the position they wish. It may also be beneficial to allow participants to use existing accessibility tools and simulate how they work in this situation. It is important that when showing prototypes designs are kept flexible enough to allow instant alterations.

Evaluation

Designers should consider different evaluation tools and not simply accept that evaluations can only take place through observations. Consider different evaluation tools, it may be possible for participants to be trained to perform heuristic evaluations. If support staff can be included in the evaluations and are willing to encourage participants to take part then there can be a role for them, many support workers will be used to completing diaries or logs as part of their daily routine and so an evaluation diary may work better in this situations than it does in a business environment for example.

7.5 Summary

The lessons learnt from Chapter Six were examined for inclusion in a set of guidelines for other developers who wished to work with adults with SSPI in the development of software. These guidelines were produced based upon the format of existing ISO guidelines.

Following the development of these guidelines they were presented to a new software development in order to evaluate their usefulness and to compare the results from Chapter Six. This new software study is presented in Chapter Eight.

Chapter 8. **Evaluation of Guidelines and Second Study**

"I liked seeing my ideas in the program".

Robert, a participant in the study with SSPI

8.1 Introduction

Chapter Six demonstrated the ability of adults with Severe Speech and Physical Impairments (SSPI) to take part in software development tasks. Given the lack of guidance available for developers wishing to work with this group in design, the author made the decision to produce a set of guidelines based upon lessons learnt in Chapter Six. These guidelines were provided in Chapter Seven, this chapter discusses the second study with adults with SSPI and the evaluation of the guidelines.

8.2 Second Study

*Work from this study contributed to a paper presented at the 2010 RaATE conference (see **Appendix E**).*

The author co-supervised HB's project and observed HB during the development. The aim of this observation was to identify information that was not addressed in the guidelines and to monitor the use of the guidelines.

HB was to create a Talking Photoalbum for adults with Severe Speech and Physical Impairments (SSPI). The aim of the software was to allow adults with SSPI to share stories relating to photographs. Adults with SSPI often struggle to share personal narratives (Black et al., 2010b) and it was hoped that this software would help to facilitate this.

People with SSPI often rely upon a carer to enter stories into the device, but this is time consuming and results in static, monologue output as the story text tends to be stored under a single key. Another way of sharing stories is through photographs,

with some use being made of “speaking photograph albums”; allowing voice recordings to be linked to individual photographs. However, non-speaking individuals still have to rely on speaking helpers and the playback still mimics a monologue.

Eight adults with SSPI and a support worker were enabled to participate in all stages of the design using innovative design methods; these included magnetic white boards, etran boards and PowerPoint designs.. Participants were initially invited to choose the focus of the project; they expressed a desire to share their stories and their photographs but indicated that they currently require assistance in doing this. The participants then helped design the software from low level paper based designs through to a fully working piece of software.

User Centred Design techniques were employed throughout the development and worked with eight participants with SSPI in all stages of the development (see Table 12). All participants used a day resource centre five days a week.

HB used a variety of methods in the development process. In the identification of the context of use she conducted a focus group with all of the participants. The requirements gathering methods included semi structured interviews and observation of participants using existing interactive photo album technology. The development used methods similar to those seen in the CHAMPION development: magnetic low fidelity prototyping, Clicker5 for mid fidelity and Visual Studio for high fidelity prototyping. A full project report from HB on the work done can be found in Appendix F.

Table 12 - Participant Demographics in HB's Study

Participant	Method of Augmentative and Alternative Communication (AAC)	Other Means of Communication
Anna	Dynavox	Vocalisation
Betty	Lightwriter	Gestures Vocalisation
Carly	Palm-top communication aid with Bliss symbols broken	Gestures Vocalisation
Danni	None	Eye gaze
Eric	Dynavox,	Limited gestures
Fred	Word board	Gestures, dsyarthric speech
George	Dynavox	Eye gaze
Harry	None	Nodding/Shaking Head

8.3 Evolution of Guidelines

While HB was using the guidelines, it was also hoped that she would be able to contribute to the further development of the guidelines. The author recognised that all of the possible information a developer would need could not be learnt from one single development project.

HB provided weekly debriefs in meetings with the author which identified the successes and challenges that she faced on a weekly basis. These weekly meeting notes were analysed using thematic analysis and verified by an independent researcher. These challenges are categorised by the stage in which they were

identified. Table 13 identifies whether the theme presented new information or if this was already addressed in the guidelines.

8.3.1. Preparation

Before HB began her work with adults with SSPI she completed the same set of teaching materials on SSPI and AAC as the author had. In addition to completing the study materials, HB met with two adults with SSPI as part of a separate research project. HB felt that this preparation had helped her to be better prepared and less nervous prior to meeting participants.

8.3.2. Identify Context of Use

Although HB had had this preparation she was still nervous before meeting participants. The author reassured HB that she too had been nervous in the lead up to her first meeting. HB reported being reassured by this.

Following the first meeting with participants HB agreed that she would email the manager looking after the participants with possible dates for sessions. HB sent this straight after the meeting but then struggled to get hold of the manager. This had not been a problem in the pilot, possibly because there was the direct link with the resource staff member on the project. The author offered to help with the management of organising sessions and contacting the manager. This meant HB was able to concentrate on the project and contact was easier for the author who had worked previously with the manager. HB commented on this being a big help.

For the first session HB asked an assistant to act as note taker and record the conversations and interactions in the session. The note taker was able to record much of the discussion but struggled to keep up with the nonverbal interaction and how the participants responded to the discussion. HB realised that a video camera would be

required for the following sessions and it was arranged for this to be available. In the second session the note taker was present again, however after the session it was decided that the video had captured everything that the note taker had, as well as other nonverbal information. For the remaining sessions the note taker was not present with a video camera used instead. In the weekly debriefs HB discussed the benefits of the video camera with the author.

Table 13- Themes from HB's Work

Theme	**New Information (Yes/No)**	**Stage Identified**
It is useful to learn about AAC First	No	Preparation
It is normal to feel nervous	Yes	Identify Context of Use
Assistance may be needed in contacting participants	Yes	Identify Context of Use
It is important to determine all the ways in which a participant communicates early on	Yes	Identify Context of Use
It can be beneficial to challenge Participants	Yes	Requirements Gathering
A video camera is very useful (essential in some situations)	Yes	Requirements Gathering
It is vital, even in lab notes to protect participant anonymity	Yes	Low Tech Prototyping
It is possible that participants will want to keep work from the session	Yes	Low Tech Prototyping
There should be consistency in design	Yes	High Tech Prototyping

At the first meeting HB was introduced to a young male participant who introduced himself using his AAC device. HB then went through the informed consent sheet. When it came to the section where participants are asked yes and no questions the participant did not appear to reply. After an uncomfortable three minutes the participant's support worker told HB that the participants did not use their AAC device to communicate yes and no. For these replies the participant used unaided AAC by looking up for 'yes' and down for 'no'. Had HB been aware of this earlier it would have saved awkwardness and confusion.

8.3.3. Requirements Gathering

Participants can be challenged in one of two ways: either as participants in the sessions or as end users using the software. For the 1st design session HB had three activities for the participants to carry out:

1) Participants were asked to select a photograph from a selection provided and discuss what extra information they would want from the photographer;

2) They were asked to use a physical talking photo album;

3) They were asked to design their own version using magnetic paper prototypes.

The author raised concern that participants might struggle with the cognitive load of the tasks and advised HB to have back up plans if participants could not cope. At the end of the sessions HB reported that the participants had enjoyed and coped with the tasks. When the author spoke to the head manager of the service that the participant were from, the manager was enthusiastic about the sessions and said that it was excellent that the participants had been challenged to achieve more.

8.3.4. Prototyping

When participants are challenged during sessions they may feel a sense of pride in their achievements and want to keep the work they have done so that they can show it to others. In some cases this is not possible for example when dealing with the actual software and Newell cautions that this may be a problem (Newell and Gregor, 2000). However, in early stages of design when work is done with paper prototypes HB was able to accommodate this by taking close up photographs of the work and allowing participants to take the originals home.

Throughout the project HB kept detailed handwritten notes in a project logbook. During a meeting the logbook was being referred to and the author noticed that the notes on participants included their real names. This was not surprising given that many of the notes had been taken during meetings with the participants. This can be dangerous as log books are easily misplaced or lost entirely, it is also in violation of the promise given in the ethical consent forms which states that all information linking participants to the study will be stored securely within the School of Computing. HB was told of the importance of using pseudonyms in all documentation which discusses work participants have done in the sessions. The only time a participant's real name should be used is in the participant consent form.

It is of course always important to protect participants' anonymity but particularly with this vulnerable group.

During an interface design review meeting the author noticed that HB had placed the text below the image on each button. The author advised HB to change this so that there was consistency between current paper symbol boards and the new technology.

Consistency in design is important so that users can quickly adapt between different pieces of software.

When people with SSPI use paper symbol boards the text is placed along the top of each symbol. This is so that when a communication partner is looking at the board they can read the text if they do not know what the symbol means. When the text is at the bottom of the symbol it can be covered and a partner cannot read it.

It is important to keep a consistent style throughout development and where possible to have this related to a user's existing knowledge.

8.4 Evaluation of Guidelines

HB was presented with the guidelines prior to the beginning of the project and read them in full. She was able to refer to the guidelines at different stages of the project, they were used most prior to the beginning of a new stage in the User Centred Design lifecycle. HB reported finding the guidelines to be very helpful.

8.5 Conclusion of Second Study

The second study had similar results to the first, with participants contributing the majority of the requirements and features (a full breakdown of these is available in Appendix F). Taking both of these studies it is possible to answer the research questions.

8.6 Summary

This chapter discussed the evaluation of the guidelines created in Chapter Seven. These lessons were given to aid a MSc student who was working with adults with SSPI. The lessons and results from this second study were presented in this chapter.

The following chapter will consider how the results of the CHAMPION study and HB's work can be used in answering the research questions.

Chapter 9. **Discussion**

"If we can see the goal of the project its worth doing".

Robert, a participant in the study with SSPI

9.1 Introduction

This chapter begins with an overview of the work done in Chapter Six with adults with Severe Speech and Physical Impairments using User Centred Design. The outcomes of this work are then discussed in relation to the literature and the research questions posed in Chapter Four.

9.2 Summary of Research

The CHAMPION study looked at the development of an electronic multimedia patient profiling software for use by adults with Severe Speech and Physical Impairments (SSPI) (see Section 6.2).

Prior to any development the first stage of the User Centred Design lifecycle was the planning of the Human Computer Interaction (HCI) process. This stage involved considering the ethical issues that could occur in the process and how informed consent would be gained from participants with little or no verbal communication.

The first stage of the development was to identify the context of use. Observation was the first method; the author spent time at a care centre for adults with complex disabilities including SSPI. During the week the author spent at the centre, she learnt about the different staff roles and how the service users with SSPI communicated with others. Following the observations, a focus group was held with six adults with

SSPI. This focus group showed that the adults with SSPI could think about the issues surrounding the software and the different situations it would be useful in.

The next stage in the development process was to gather the requirements. Two methods were used for this, forum theatre and storyboarding. Three participants with SSPI were shown a forum theatre video and were able to identify with the characters in the video and imagine alternative endings to the stories presented. A set of seven storyboards were created. Participants were shown the storyboards and asked to think of software requirements for each of these stages.

The prototyping stage in the development of CHAMPION was divided into three phases: low fidelity, mid fidelity and high fidelity.

In the low fidelity stages, participants used magnetic paper prototyping techniques developed by the author. In this stage participants suggested two functional and two non functional requirements. The mid fidelity stages involved the use of Clicker5 software and incorporated the participants' access methods. Participants contributed three functional alterations and two design alterations. The high fidelity prototypes were produced in Visual Studio. In the first iteration of the high fidelity prototyping again the participants showed the ability to critique the software; they were able to identify whether the problem was a design or a functional problem and suggested solutions to the issues.

The short term evaluation took place over the course of three days at the care centre, four participants took part in these evaluations and had 30 minutes training on the software. During this longer term evaluation there were problems with equipment at the centre and this meant that no sessions of more than 5 minutes were attempted.

Despite the problems with the longer term evaluation, the results from the shorter term evaluation were promising and showed that the initial usability of the software was good.

Following the CHAMPION study a set of draft recommendations were created and used by a MSc student on her own software development project with adults with SSPI. This study added further information for recommendations for other developers and showed that it was possible for other developers to carry out full User Centred Design with adults with SSPI.

Taking these studies it is possible to answer the research questions identified in Chapter Four.

9.3 "Can the problems cited in the literature be overcome to allow User Centred Design to be conducted with participants with SSPI?"

The first research question looked at "Can the problems cited in the literature be overcome to allow User Centred Design to be conducted with participants with SSPI?". The problems highlighted in Chapter Four were examined alongside the results from both the author's and HB's study to see if it had been possible to overcome all of them.

9.3.1. Representative Sample

Gathering a representative sample when working with users with SSPI can be difficult. There are many different levels of physical, cognitive, sensory and communication impairments in SSPI (Newell and Gregor, 2000).

In the CHAMPION project, an attempt was made to gather a representative sample of the user group. This meant aiming for a spread of ages and ability, a good mix of male and female participants and a range of different methods of communicating. While it is unlikely that every combination of communication methods and impairments can be included in the one participant pool, it is important to get as representative a sample as possible. With careful planning with support staff it is possible to gain a representative sample.

9.3.2. Achieving Consensus

Another issue that arises from the wide variation found in people with SSPI is that it can make it difficult to achieve consensus on requirements (Newell and Gregor, 2000). This group may find it more difficult to hold discussions on their different needs and be able to discuss the pros and cons of tailoring to each disability (Waller et al., 2005a).

With support and guidance the CHAMPION project showed that participants are able to discuss the different needs and how these should be reflected in the requirements (Prior, 2010).

The other issue is that there can be a danger that a researcher will pay attention to the articulated needs of one participant (Newell and Gregor, 2000). In the study the author found that participants were very good at considering the needs of others and how they would use the technology. They were able to consider different disabilities or abilities. This reduced some of the risk highlighted here. The other help with this problem is for researchers to be aware of the problems when one participant is dominating the conversation. Researchers need to ensure that all the participants

raise their views and that they encourage more confident participants to listen to the views of the shyer participants and encourage them to share their views.

9.3.3. Communicating Thoughts

Newell (2000) suggested that a user may struggle to communication their thoughts. The author understood this concern to mean that a participant may not be able to offer suggestions for how features of a design could be improved, or discuss their views on the way a design is progressing.

It is true that it does take longer when working with these participants for them to be able to share their thoughts (Balandin et al., 2007). The author found in the CHAMPION study that they need to be supported in feeling confident to communicate what they are thinking. The researcher needs to continually encourage participants by reminding them that there are no wrong answers and that any problems they are experiencing with the technology will be useful in helping the researcher to make better designs. Communicating exactly what they are thinking does not come naturally to a wide variety of users, but this may be more true for adults with SSPI who may not have had much experience of being asked to clearly articulate what they are thinking (Waller et al., 2005a). The author found that with time and help the majority of users were able to do this.

Sometimes prompts may help the participants to communicate their thoughts more clearly. In the CHAMPION study rather than be asked directly what information they would want to share with medical staff, participants were shown a storyboard of the hospital experience and asked at each clip on the comic strip what information they think would aid the situation at this point.

9.3.4. New Technology

Augmentative and Alternative Communication (AAC) is a rapidly developing field and many of the new devices onto the market are featuring technology that would not have been imagined a few years ago (for example the Dynavox Eyemax (Mayer-Johnson, 2010) features advanced environmental controls, wheelchair control and cameras to assist vision). Participants may find it difficult to provide requirements for technology which they have not seen before (Rice et al., 2007). Again this is a challenge for all developers, but the additional problem when working with participants with SSPI is that their access to new developments in the wider technology field may have been limited (Waller et al., 2005a).

By using storyboards, scenarios and forum theatre some of these problems can be tackled. These techniques helped participants to use their imagination and visualise how new technology might be used in the future.

9.3.5. Ethical and Legal Issues

Newell (2000) suggests that some of the traditional methods used to uncover a user's thoughts or opinions on a device or software may be unethical when working with this user group, for example letting the participants make mistakes or struggle. To deal effectively with this takes time.

In the CHAMPION study this problem was dealt with by building up a relationship between the author and participants. Once the participants become comfortable with the author, the author would encourage them to find things that were broken or things that they found difficult. Once participants got to know the author they enjoyed 'breaking' the software and pointing out the author's errors.

Another issue that it is suggested may be unethical is that often the measure of success of a piece of technology will be the disappointment that is displayed when the technology is removed (Newell and Gregor, 2000). This is a problem, particularly when designing technology that may provide access to communication for people with SSPI.

One solution may be to look at less expensive ways of continuing to provide the software, for example having it run on laptops.

For some people with SSPI it is not possible to gain informed consent (Balandin et al., 2006). In Scotland (and other countries), legislation exists which allows a guardian to be appointed for an adult over the age of eighteen who is deemed by a judge to be incapable of making legal and medical decisions on their own behalf (Adults with Incapacity Act (Scotland), 2000). This guardianship order is appointed through a court order and specifies the different areas in which the guardian has the ability to make decisions on behalf of the adult in question. Some guardianship orders have the provision for the guardian to consent to the adult taking part in research. Even when this order is in place however, it is good ethical practice to receive "assent" from the participant in the same manner as happens with participants under the age of sixteen (Waller et al., 2009).

9.3.6. Payment

Research projects frequently offer participants remuneration in some form in return for their assistance in research work (Molich et al., 2001). There is significant debate over the issue of payment of participants in research (Dickert and Grady, 1999). A major concern in paying participants is that participating in research may cause less economically stable participants to feel undue pressure to volunteer, this is a

particular concern in medical research which can often come with important risks (Dickert and Grady, 1999).

In software engineering where the risks tend to be much lower than in medical research (Molich et al., 2001) there is less controversy over the payment of participants in software research (Gebhardt, 2003, Ross, 2010), indeed it is usually expected (Newell and Gregor, 2000). This can cause problems when working with adults with SSPI as it may interfere with benefits rules (Newell and Gregor, 2000). It is permissible to pay expenses for time spent working on the research project and this should be done.

In the CHAMPION study it was found that the participants were happy to work for no payment and got enough pleasure from feeling that they were being useful and from participating in the wider society.

9.3.7. Purchase of Software

In the past in assistive technology the end user was not involved in any stage of the purchase of Assistive Technology (Cudd (ed), 2010). Now the end user is gradually being involved in expressing some of their problems with current technology but they are still not generally the purchaser of the technology (Cudd (ed), 2010). Assistive Technology is usually bought by NHS therapists for their clients (Murray, 2008). This can now be compared to the way technology for children finds its route to market. The children may be involved in design and development but it will be their parents who make the purchase of the technology. The children will however tend to have a say in the purchase (Druin et al., 1998).

Research is also ongoing into how a new model of route to market for assistive technology can be developed as seen by the recent Association for the Advancement

of Assistive Technology workshop on Assistive Technology and Technology Transfer (Cudd (ed), 2010)

The first research question identified in Chapter Four investigated if the problems highlighted in the literature could be overcome. Through analysis of the process of the author's and HB's study it has been possible to address these problems. The satisfaction that the users reported having when working on the User Centred Design is a crude measurement, however there are no other reported measures in the literature which can be used to assess the effectiveness of User Centred Design. Therefore it would appear that the problems cited in the literature can be overcome to allow User Centred Design to be conducted with participants with SSPI.

9.4 Can methods currently used in Human Computer Interaction be combined and adapted to allow people with SSPI to contribute to the design of technology?

The second research question was concerned with how current methods used in Human Computer Interaction (HCI) could be adapted for use with participants with SSPI.

A review of some of the common methods in HCI was presented in Chapter Five. It is not possible to quantify exactly how many HCI methods are currently in use, developers and experts in HCI are continually striving to produce new methods. The author chose the methods they believed to be the most commonly used and analysed these for use in the CHAMPION development.

The CHAMPION project used ten methods in total in all the stages up to the longitudinal evaluation (see Chapter Six) and participants with SSPI reported feeling

useful and that they were contributing in all of the methods, although they conceded that many were challenging. There was not a measure take of the degree of involvement the participants felt. It is possible that a likert scale could have been used to provide measures for this involvement but the author was more interested in the analysis of the results from the debriefing focus group.

None of the adapted methods had to be abandoned and participants were able to complete all of the tasks in the methods. The one stage that was not completed was the long term evaluation, this stage did not complete due to staff finding it difficult to find the time needed to support participants in using the software. The participants were able to use the software independently and were in many cases able to set up the hardware themselves. However, in the care centre the service users are not allowed to use the hardware without supervision for fear of breaking the technology. On the occasions when the author had to return to the care centre to correct a problem with the hardware, the participants were able to demonstrate to her that they knew how to fix the problem but were not allowed to. In the shorter evaluation all participants were able to complete the methods that were intended to be repeated throughout the longitudinal evaluation.

The methods were not greatly adapted with the exception of the focus group and low fidelity prototyping. For the majority of the methods they were conducted in a manner similar to that found in a general development (Sharp et al., 2007). The main difference was the way the questions were phrased and the time taken to interpret the answers given by participants. This did require considerable preparation time, in a traditional development the preparation to session time ratio is reported at 3:10 (Gebhardt, 2003). In the CHAMPION development the ratio of preparation to

session time was on average 8:1, HB's project was higher at 14:1 although this may have been due to HB having less experience than the author in User Centred Design. This extra time should be factored into the project planning.

As previously discussed (see Chapter Six), often it is not possible to cover as much detail and information in one session with adults with SSPI as would be covered when working with adults without disability. This means that a researcher must be willing to plan additional sessions to ensure all the information is covered.

In each stage of the development the participants made a larger contribution to the requirements, ideas and suggestions than the author. Table 14 shows the percentage of requirements and suggestions for features that came from the participants in each of the sessions. The lowest level of contribution was in the mid fidelity stage, the author believes that there are two possible reasons for the reduction in involvement in this stage. The first possible reason is that participants may have been struggling to make the adjustments to the more polished appearance of the software. In this stage, Clicker5 was used may have made the participants more hesitant of providing negative criticism, however their level of involvement significantly increased by 27% in the next stage. The possible other reason is that two of the participants were feeling unwell during the session. Both were keen to take part but it became clear during the session that they were not as willing as they had been previously to engage in conversation.

The calculation of the degree of participant involvement was taken by analysing the transcripts of the sessions, looking at the changes made after each session and the discussion that preceded this change. This analysis was verified by an independent

researcher. HB conducted a similar analysis and found a contribution of 68% (see Appendix F).

Table 14 - Degree of Participant Involvement

Observation	Focus Group	Forum Theatre	Story Boards	Low Fidelity Prototype	Mid Fidelity Prototype	High Fidelity Prototype #1	High Fidelity Prototype #2	Evaluation	**Total**
60%	100%	100%	100%	100%	58%	83%	100%	Unable to Complete[13]	**78%**

As stated previously it is not known if the participants in either study would have been able to cope with more traditional methods or if traditional methods would have yielded an even greater response from participants. With correct planning, consideration of the risks and with participants who understand the experimental nature of the methods it may be possible to explore methods not used in this thesis. A review of the implementation of the methods used in CHAMPION were included in the guidelines discussed in Chapter Seven, guidance on how other methods could also be adapted were included in the guidelines. Updated guidance on how to carry out these methods with this group are presented in Appendix L**.**

Research question two was investigating if methods currently used in Human Computer Interaction (HCI) could be combined and adapted to allow people with SSPI to contribute to the design of technology. Through analysis of the features in the CHAMPION study it can be seen that participants made a significant contribution to the features of the software. This work has shown that several

[13] As the end evaluation was not possible to complete, it was not included in this calculation

methods currently used in Human Computer Interaction can be combined and adapted to allow people with SSPI to contribute to the design of technology. Further work would be required to investigate if all methods currently used in HCI are suitable for this user group.

Having answered these research questions it is now possible to consider the implications of this work.

9.5 Summary

This thesis chapter has provided a summary of Chapters Five and Six. The results of the work in Chapter Eight were discussed and their relation to the research questions presented. The final chapter of this thesis, Chapter Ten will present the implications of this work in relation to practice, policy and research.

Chapter 10. **Implications and Conclusion**

"One last thing, thank you for listening".

Doug, a participant in the study with SSPI

10.1 Introduction

As stated in Chapter Nine, the work contained in this thesis and the outcomes of the research questions has implications for a variety of fields.

This chapter provides the implications of this research for the fields of academic research, policy and practice. Areas for future study are presented in these implications.

10.2 Implications for Policy

10.2.1. Healthcare

This work has shown that adults with Severe Speech and Physical Impairments (SSPI) can make decisions based on the evidence that they are presented with and the opinions and needs of others. This information needs to be made clear to healthcare professionals, often in healthcare adults with SSPI find that their relatives are being asked to make decisions on their behalf, despite the fact that they are capable of making these decisions independently (Hemsley et al., 2008a). In the studies reported in this thesis, the adults with SSPI were also able to communicate the reasons behind their opinions, this communication needs to be supported by both their support staff and the medical professionals, and additional training may be of benefit here.

10.2.2. Education

In the CHAMPION study, adults with SSPI were encouraged to voice their own opinions and make decisions independently. This did not appear to come naturally to

two of the participants, both of whom had been educated in special needs schools. The participant who took to sharing his opinions the quickest had been educated in mainstream schools. By the end of the work all of the participants were actively advocating their opinions. One participant reported feeling that the work in the CHAMPION study had been a form of 'training' for advocating their opinions. It may be that more work in advocacy in special needs schools could benefit these young people as they transition from school to adult services.

10.3 Implications for Practice

10.3.1. Care Centre User Committees

Currently many care centres have service user committees (e.g. Capability Scotland, 2011) where service users can raise problems and concerns that they have. Typically the staff will then offer to produce solutions for these problems. This work suggests that service users with appropriate support and encouragement can take more responsibility for gathering the views of the entire community and bring them to committee. It may also be possible for these representatives to take more responsibility for finding solutions and taking the steps required for these solutions to be put in place. This would empower the adults with SSPI to take more responsibility for their own lives. As stated in Chapter One, adults with SSPI frequently report feeling a lack of empowerment (Edyburn, 2006) and this can lead to depression (Wressle and Samuelsson, 2004). This work has the potential to influence policy in this area.

10.3.2. Healthcare

The CHAMPION system which was developed in Chapter Six is now at the high level functioning prototype stage and is ready for the development needed to have it

running widely. One way in which the software could be quickly brought out for use by care centres would be to have the software available in the centre along with the specialist computers needed for it to run on hospital wards. Service users at the centres could prepare their own multimedia profiles over time on the centre's computers. When a service user was admitted to hospital this profile could be transferred onto a specialist computer quickly and then taken to them in the hospital. A longterm goal would be to have the CHAMPION information stored with each patient's electronic medical record so that this information was available to GPs and hospitals across the country; however as discussed in Section 3.4, the electronic medical records system for the NHS is still far from completion.

10.3.3. Employment

One particular area of practice in which this work has implications is that of employment. There is evidence in the literature that adults with SSPI are often unemployed (McNaughton et al., 2002a, Holmes et al., 2010). One reason cited for this is due to a lack of confidence on the part of the adults or their families (McNaughton et al., 2002a, McNaughton et al., 2006). This work has shown that with encouragement, adults with SSPI can grow in confidence and develop social skills.

Another issue identified was the lack of usability of AAC devices (McNaughton et al., 2002a), this relates to the problems identified in Chapter Two. The devices currently do not allow the spontaneity needed in the work place (McNaughton et al., 2006). If the usability of AAC devices can be improved through User Centred Design then it may be that the devices are better suited to enabling adults with SSPI to enter employment.

The Communication Champion[14] for children and young people aged 0-19 in England, Jean Gross, has made available the figures for AAC costs and provision in England. The Department for Education in England estimate that £500,000 is saved over the course of a lifetime for every person who changes from permanent unemployment to permanent employment (Gross, 2010). Gross suggests that this means that if even just one in ten children who require AAC in England were able to enter employment it would save the government £310 million over the course of their lives (Gross, 2010). The current cost of providing all children in England with appropriate AAC and support is estimated at £10 million. This means that with appropriate AAC and support, employment could be provided for these children, then the potential cost savings would be large.

Producing more usable AAC devices will require the input of Human Computer Interaction (HCI) developers. This work has important implications for HCI research.

10.4 Implications for Research

10.4.1. Health and Social Research

This work has shown that adults with SSPI can provide informed consent and communicate their thoughts clearly. This indicates there is potential for them to be more actively involved as participants than has often been the case previously.

In addition to this, there is the potential for them to act on advisory panels in medical research, as is common in other fields (Central and North West London, 2004). Other

[14] The Communication Champion is responsible for improving services for children and young people who have speech and communication needs. The Champion will work with variety of stakeholders and agencies to do this (Bercow Report, 2008)

groups recommend training for service users, some of the training in advocacy used in this work could be of use here. Similar training could also be of benefit to adults with SSPI wishing to enter employment.

10.4.2. Further Development of Guidelines

It is likely that as more projects are conducted with participants with SSPI, more lessons will be learnt which could feed into these guidelines. Therefore the guidelines are currently being produced as a wiki webpage which developers can have access to and contribute back their own experiences and lessons that they learnt when conducting this work.

In order to empirically measure the effectiveness of the guidelines, a large multi centre study is likely to be necessary with control groups developing AAC software without any User Centred Design, groups conducting User Centred Design without the guidelines and groups conducting User Centred Design with the help of the guidelines.

10.4.3. Implications for HCI Research

This work has produced a set of recommendations for developers, when HB was asked for her opinion of the guidelines she stated that "*the guidelines were very useful in helping me prepare for the challenges I faced.*".

HB's work had additional lessons for HCI developers and these have been added to the recommendations. The recommendations will need continual modification as more work is done with adults with SSPI. The current version of the guidelines can be found in Appendix L.

This work has shown that it is possible for HCI developers to work with adults with SSPI in the User Centred Design of software and this is something that all developers working in AAC software should give consideration to.

As seen in the CHAMPION development the care centre was not always the ideal environment for these sessions to occur. There were frequent interruptions and the rooms often had to be rearranged to allow for sessions to take place. For the final evaluations it is important that these take place in a user's own environment but for the earlier stages there may be an advantage in conducting the work in a specialist centre. This is something HCI developers should consider when planning a project. This is an area for future research.

The other disadvantage was that holding the sessions in a centre meant the participant pool was limited to those attending the centre. Adults with SSPI who do not attend care centres are restricted in their ability to take part in research if it is limited to these locations.

One solution to this would be to set up a dedicated User Centre within an accessible building so that adults from different centres and those who do not attend centres could meet and participate in research together. The model for this could be based on the existing Older Adults User Centre at the University of Dundee's School of Computing (Forbes et al., 2009).

A pilot study is now underway to look at the feasibility of having an AAC User Group meeting regularly at the School of Computing. The group currently meets once a fortnight. The group sessions look at developing the members' own IT skills and at including them in a wide range of research projects, including undergraduate

projects. A full description of the work taking place at the centre is available in Appendix K.

The goals of the AAC User Centre are firstly to provide a means for adults with SSPI to engage with the wider community and develop their own skills. Secondly it is to provide a resource for researchers who wish to work with adults with SSPI in their projects. The third goal is to educate students on the needs of people with SSPI and allow them the opportunity to work with adults with SSPI.

The centre is currently still in its pilot stage and is currently run by members of the School of Computing AAC research team, in the future it is hoped that the centre can be expanded and a member of staff can be dedicated to the running of it.

Another area for future investigation is to look at if improvements in usability reduce abandonment. As was stated in Chapter Four the aim of this work was not to investigate if User Centred Design meant a reduction in abandonment of AAC technology. This work was the first stage in the process of investigating this. Now that it was been established that User Centred Design can be conducted with adults with SSPI the next stage would be to conduct a large randomised control trial looking at AAC developments which used User Centred Design with end users and AAC development which worked with traditional participants (e.g. Speech and Language Therapists). The different devices would then need to be used with a large set of participants who used AAC to look at the different rates of abandonment over time.

Conducting a trial of this nature would be incredibly complicated, people with SSPI are a very heterogeneous group (Glennen and Descoste, 1997) and finding enough

participants with a wide enough range of impairments would prove challenging, indeed it may be that the study would have to be international.

To find a large enough pool of AAC developers would also likely require that AAC manufacturers came onboard and provided their staff to be developers.

An alternative would be to encourage other researchers to consider using User Centred Design with end users with SSPI and if a large enough pool of case studies could be gathered, to perform a case study analysis.

10.5 Summary

This thesis has investigated the issue of abandonment in Augmentative and Alternative Communication (AAC) and how this may be linked to poor software usability. The most common method in software development for improving usability is to use User Centred Design with end participants. In the development of AAC software there has traditionally been limited work done in User Centred Design and many reasons for this are cited in the literature.

This thesis has reported on a pilot study which involved adults with SSPI throughout the development of a piece of information sharing software. This work resulted in a set of recommendations which were then provided to a MSc student in a design study. Using the recommendations the student was able to complete a second User Centred Design study involving adults with SSPI. The student found the recommendations to be highly usable. The results from these studies were used to inform the answers to the research questions.

This work has implications for medical research, employment for adults with SSPI, social care and in particular Human Computer Interaction.

To further develop the techniques in conducting User Centred Design, a specialised centre has been created and is currently in a pilot study.

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Appendix A. Overview of User Centred Process,

Presented at ACM CHI Conference 2010

HCI Methods for Including Adults with Disabilities in the Design of CHAMPION

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Abstract
The demand for software, suitable for users with complex communication needs and other disabilities, is increasing. However, traditional HCI design methods are not always suitable for these users. To address this, the CHAMPION project is piloting adapted methods in the development of a patient hospital profile for this user group. Initial results show that users with cognitive and communication disabilities can be involved in participatory design. The challenge is now to develop meaningful evaluation methods for this group.

Keywords
Disability, usability, inclusive design, methodology
General Terms
Design, Experimentation

ACM Classification Keywords

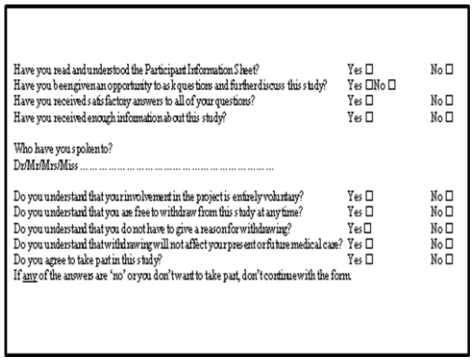
D.2 SOFTWARE ENGINEERING
D.2.10 Design: Methodologies

CHI 2010, April 10–15, 2010, Atlanta, Georgia, USA.
ACM 978-1-60558-930-5/10/04.

Introduction

Adults with Complex Communication Needs (CCN) have been overlooked as research participants in the past. The CHAMPION project is investigating the potential to include participants with Complex Communication Needs and cognitive impairment in the design of a new health software program.

Working with these adults in participatory design is challenging; traditional HCI methods are not always suitable due to communication problems and the cognitive load involved for the participants using them. Using an AAC device to communicate is time consuming and requires a great deal of concentration by a communication partner. In addition to this, participants who are unused to taking part in any form of research need to be encouraged in providing feedback on systems.



Have you read and understood the Participant Information Sheet? Yes ☐ No ☐
Have you been given an opportunity to ask questions and further discuss this study? Yes ☐ No ☐
Have you received satisfactory answers to all of your questions? Yes ☐ No ☐
Have you received enough information about this study? Yes ☐ No ☐

Who have you spoken to?
Dr/Mr/Mrs/Miss .....

Do you understand that your involvement in the project is entirely voluntary? Yes ☐ No ☐
Do you understand that you are free to withdraw from this study at any time? Yes ☐ No ☐
Do you understand that you do not have to give a reason for withdrawing? Yes ☐ No ☐
Do you understand that withdrawing will not affect your present or future medical care? Yes ☐ No ☐
Do you agree to take part in this study? Yes ☐ No ☐
If any of the answers are 'no' or you don't want to take part, don't continue with the form.

Figure 1 Adapted Informed Consent Form. Participants were asked a series of multiple choice questions to which they could answer yes or no, such as "Can you withdraw at any point?", to ensure they had understood their rights in the study

Within the area of Augmentative and Alternative Communication (AAC) and Complex Communication Needs (CCN), there is has been some use of User Centred Design (UCD). Alm et al., (Alm et al., 1995) included adults with CCN in focus groups which provided ideas which were fed into the software design process. Other projects have used adults with CCN to evaluate early stage paper prototypes (Waller et al., 2005b). But, to the best of our knowledge, little UCD work has been done with adults with CCN who may also have cognitive impairments.

Importance of Work

The number of computer users with cognitive and developmental disabilities is increasing e.g. day and residential units are now including computer courses as part of the program for service users (Parsons et al., 2006). As adults with developmental disabilities become more integrated into the workplace, the demand for computer software which is accessible by a wider spectrum of users is likely to increase.

However, the main use of technology by this user group remains in assistive technology and AAC devices. As with other user groups, a lack of UCD may contribute to the poor adoption of technology. The rate of abandonment of AAC devices is reported to be as high as 53.3% (Riemer-Reiss and Wacker, 2000). It is suggested that the inclusion of end users in the design process may reduce this abandonment rate (Waller et al., 2005b)**.** While there is literature on developing UCD methods for older and disabled users together, there is little research into developing UCD methodologies for adults with CCN who may also have cognitive impairment (Waller et al., 2005a).

Adapted HCI Methods

Traditional HCI methods such as focus groups, design sessions and rapid prototyping were adapted and piloted with a group of adults with CCN and learning disabilities from a local disability day centre.

Informed Consent: As the adults with moderate to profound communicate impairment were unlikely to be able to consent through traditional channels, a modified consent process was followed (see Figure 1).

Focus Group: 6 adults with CCN (3 males and 3 females) took part in a focus group looking at the issues surrounding hospitalization and the information they would like to share with hospital staff. The focus group was held in the day centre,

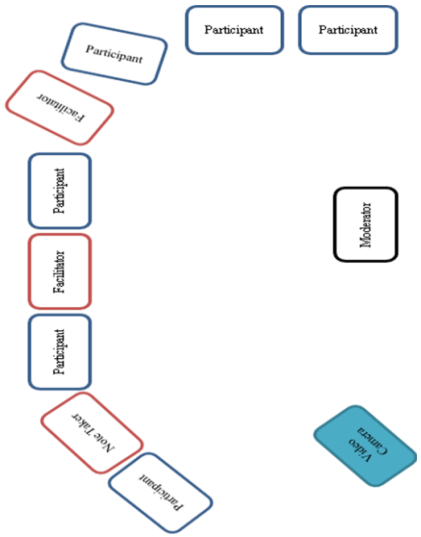


Figure2 – Layout of Focus Group. As all of the participants used motorized wheelchairs a semi circle was formed with facilitators placed next to the participants who required the most help with their communication. The moderator sat at the head of the circle with the video recorder placed to the left of the moderator to ensure all the participants were captured. One participant had a hearing difficulty in

in a room used for activity sessions (Figure 2). Participants were provided with questions in advance to allow those who rely upon AAC devices to prepare longer answers in advance.

Requirements Gathering:

3 participants from the first focus group formed the design group along with a support worker. This group had never been involved in a design project before or in giving requirements for a system. They had limited computer experience beyond the assistive technology they used on a day to day basis. The first meeting of the design group involved a discussion using a storyboard showing how the CHAMPION patient profile system might be used in hospital. Once the participants were clear on its use, the author stepped through how the use of the system would be used to store information. At each stage of the discussion the participants were asked for their requirements at this point.

Design: A week later a second design meeting was held with paper mock ups of the user interface. Using magnets on the back of foam shapes representing buttons, text boxes and labels, the screen layouts were displayed on a large magnetic board. Using the magnetic board meant that participants in wheelchairs could have the 'screen' placed directly in front of them.

The design process then moved onto a medium level prototype. Clicker5 (Crick Software, 2009), usually used as a way of creating writing tools for children with disabilities, was used for the prototype. Its interactivity options were harnessed to create prototypes in a similar manner to PowerPoint. The main advantages of Clicker5 over PowerPoint for this group are its ability to be controlled by assistive technology peripherals that use scanning; and its voice output of the items on the screen. During the evaluation of the Clicker5, prototype participants chose 3 different peripheral options: scanning; mouse and keyboard; and touch screen. Participants were seen individually during this session to allow better observation of how each used the peripheral device.

Participants' responses to adapted methods

During the focus group participants engaged in discussion with each other around issues prompted by 3 present questions: 1.) The good experiences of hospital, 2.) The bad experiences of hospital and 3.) What would have made the bad experiences better? The moderator took care to ensure that the

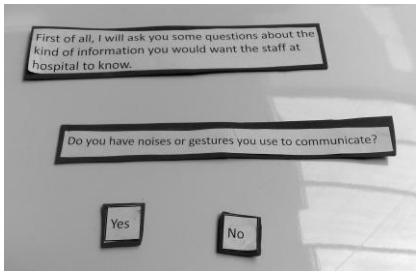


Figure 3 Paper prototype of questionnaire screen

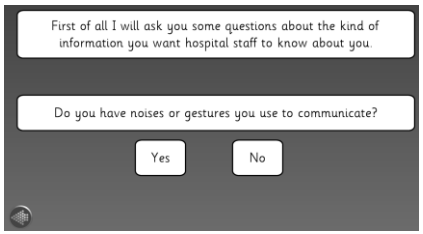


Figure 4 Clicker5 development of screen in Figure 3

participants did not interrupt each other. The participants were patient in waiting for each other to either prepare an answer on an AAC device or to have their reply spoken by a facilitator.

In the requirements session, the 3 participants were able to envisage themselves using the system and were able to discuss the different needs they had for the system. When participants disagreed about the amount of support they would require when using an aspect of the system they were able to hold a discussion with each other and attempted to reach compromise on how best to meet one another's need. This is despite the fact that these participants are rarely involved in group discussions in their typical routine.

When working with the paper prototypes, participants were able to adapt quickly to imagining the results that could occur from selecting a button or pressing a text box (Figure). As they progressed through the paper prototypes participants provided useful suggestions on better ways of providing instructions or how things should be laid out. Participants agreed that working with paper designs initially reduced their stress about making mistakes and helped them to feel more confident in making suggestions on alterations.

When using Clicker5 for evaluations participants responded well to seeing their ideas progress. Although the designs were based on discussion from earlier sessions there were differences which caused participants to be unsure at stages. Despite the more technical appearance, participants still appeared comfortable in pointing out features they did not like and providing useful suggestions for improvement.

Next Stages

The remainder of this thesis will focus on moving the designs into computer software. The challenge is to ensure continued participation from adults with complex disabilities as the project moves onto more technical stages. Unlike other software projects where one main peripheral is used for development, with others added as the project nears completion, the CHAMPION project will have to adapt the software for many different forms of assistive technology throughout its development if it is to be evaluated by participants with varieties of disability.

Another challenge for CHAMPION will be how to conduct meaningful evaluations with

participants over a period of time. It is likely that participants will initially be keen to create a profile and store their stories and information on the system; however it is not yet clear how willing they and their support staff will be to maintain their personal records. It may be that additional motivational tools will have to be built into the system to maintain users' interest.

Expected Contributions

To summarize, the expected contributions of these adapted methods are:

(1). Understanding how users with complex communication needs and additional cognitive impairments can contribute meaningfully to the development of new and innovative software.

(2). Adaptation of HCI methodologies, better suited to the cognitive and physical needs of a group of users previously overlooked in design

(3). Increased awareness of the role adults with complex disabilities can play in the design of not only assistive technology but in technology designed for the general population.

The number of computer users with physical, cognitive and communication disabilities is increasing. As more adults with disabilities gain employment in roles using computers the demand for software to be accessible to a broader range of people will increase. It is likely software designers will have to begin take on board the impact of users with disabilities when designing software. Many traditional HCI methodologies are not suitable for adults with limited experience of taking part in research or design groups and who have a range of physical and cognitive disabilities. By addressing these issues adaptations can be made to traditional usability methods to ensure they are suitable for this group.

Acknowledgements

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Appendix B. Rationale for CHAMPION

Presented at 2009 NHS Scotland Conference

Young adults with SSPI, in particular those with cerebral palsy, are 10.6 times more likely to be admitted into hospital as an inpatient and 2.2 times more likely to attend an outpatient clinic than their peers with no disability (Young et al., 2007). There is also evidence of adults lifelong disabilities suffering from more health problems into adulthood (Hemsley, Balandin, & Togher, 2007). In addition to this there is increasing evidence that people with SSPI are at a higher risk of having illnesses, which go undiagnosed or untreated, in particular those with lifelong disabilities (Cumella & Martin, 2000). As adults with cerebral palsy and other lifelong conditions age, their needs and medical care required alter too, often increasing dramatically with age (Bakheit et al., 2001; Strauss, Ojdana, Shavelle, & Rosenbloom, 2004).

Unlike paediatric care where a patient is likely to have one primary care doctor at a hospital who takes responsibility for their care, adults with cerebral palsy are likely to have different doctors for each of their medical problems (Fitton, 1994). Communication is vital for a successful medical professional/patient relationship (Iezzoni, O'Day, Killeen, & Harker, 2004) with poor communication being associated with an elevated risk of suffering an avoidable error in care in hospital (Bartlett, Blais, Tamblyn, Clermont, & MacGibbon, 2008) or even death (Zinn, 1995). The ability to answer at a minimum yes or no to questions is recognised in medical settings (Uruma et al., 2007) to allow for basic communication, however, for an estimated 600,000 adults in the United Kingdom their SSPI is so profound that

they cannot do this without some form of Assisted or Augmentative Communication device (AAC) (Aldous, 2008).

Various supports are currently used in hospitals by either the medical staff or the patient and their support worker to help to alleviate the communication difficulties such as the constant presence of regular care givers (Hemsley & Balandin, 2004; Hemsley et al., 2007) communication passports (Gates, 2006; Great Ormond Street, 2008; Millar, 1997) and more effective training for nurses (Hardy, 2001). However their effectiveness has not been widely assessed.

As the number of adults with SSPI grows the need for their stays in hospital to be made more satisfactory with improved understanding of their needs and their methods of communication becomes more urgent (Hemsley et al., 2007).

A care book can provide medical staff with up to date information on how to treat the patient, and the information can be tailored to that particular patient's needs and methods of communication, unlike generic training which would only provide an overview of the treatment and communication methods of adults with SSPI. Research into the use of care books in residential care setting has shown promise (Millar, 1997). However these situations have the benefit of the reader having the time to find and read the information. Nurses complain that often too much information is contained within the files and that accessing the pertinent information takes too long (B. Hemsley, S. Balandin, & L. Togher, 2008b). The other issue is that frequently when these profiles have been created on paper they are stored in the adults' home. However when these patients have been admitted as emergencies they find problems in communicating to the paramedics the importance of taking this profile with them (Hemsley et al., 2008a).

Of the three main current methods of supports (Finke, Light, & Kitko, 2008), the use of a care book would appear to have the most easily addressable disadvantages. Electronic medical records (EMR) and electronic health records (EHR) (collectively known as Electronic Patient Records (EPR)) are being increasingly used in general practice surgeries and in hospitals, to the extent that a House of Common Health Committee report was commissioned to investigate their impact and best practice for their use (Great Britain Parliament House of Commons Health Committee, 2007). The report from the House of Commons Health Committee gathered feedback from various interest groups on the impact they foresaw the introduction of EPRs having on the groups they represent.

There is now growing evidence of the impact of these records both for patients and staff, as well as the problems and benefits being brought by these systems. The use of EMRs has been much debated by researchers over the past decade (Larum, Ellingsen, & Faxvaag, 2001; Morrison, Jones, Blackwell, & Vuylsteke, 2008; Pollak & Lorch, 2007; Willison, Keshavjee, Nair, Goldsmith, & Holbrook, 2003) however studies have focused primarily on the use of general EMRs which provide information on the medical records currently stored as paper documents.

Current EPRs contain information on allergies, drug reactions, current medication, basic medical history, key operations, physiological details and basic lifestyle details (Harrison, 2007) this information is largely created from the GP's records and is automatically formatted and inserted into a EPR. When doctors have had access to EMR, reviews have shown that their main use of it has been for reading patient records (Larum et al., 2001).

The advantages of EPRs come from the reduction in medical errors they lead to. Information written by hand can be difficult to read in emergency situations and the legibility of a person's handwriting can have a significant effect on the information obtained from a record (Evans, Nichol, & Perlin, 2006). EHRs have also been linked to an increase in patient education, reduction in the number of procedures which have to be carried out twice due to lost information, higher levels of quality control and an improvement in the efficiency of daily ward rounds, these improvements have been most significant when the development of the systems have involved front line medical professionals (Department of Veterans Affairs, 2006).

One of the major concerns of EPR is their security, medical staff and patients have asked questions and raised concerns over the security and safety of the data being stored (Harrison, 2007). While, in general, hospitals have still not reached the levels of computerisation that GP's practices have with some wards still operating entirely on paper records, clinical networks for specific patient groups across the country have seen the development of more advanced system which can share information between different hospitals (Harrison, 2007). The main criticisms of EMR are in regards to patient control over their data that is stored in the system (BBC, 2006), a review by the Government's Health Department into the use of EMR cited patient control over data as one of the major problems facing the implementation of EMRs (Harrison, 2007). In France this problem has been overcome through giving patients legal ownership of their EMR – in France known as Dossier Médicale Personnel (DMP) – and allowing them to have their own say in who can access the information - in addition a medical professional cannot use the record without the patient's explicit consent and in their presence (Harrison, 2007). Another criticism of the use

of the system has been the time taken to read the data electronically – reading on a screen is up to 40% slower than reading on paper (Larum et al., 2001) and the screens can be very confusing with a lot of information shown at once. This problem could be eased through more use of multimedia information.

Research has been done with EMRs displayed in 19inch monitors which were next to the patient's bedside (Morrison et al., 2008), these monitors could be adjusted and their height altered to suit the viewer. We are now at a point with technology where hospital networks could cope with storing large files including video and voice, and electronic records could allow the use of both text and audio files (Walsh, 2004).

In recent investigation by MENCAP the potential for multimedia patient profiles (MMP) to be created by service users and their care attendants and to be used for planning, introducing new staff to the users and enhancing existing staff's knowledge was explored (Cavet & Grove, 2005). The study used an initial group of 6 service users, although one later retired from the project. There were some concerns raised by the staff who assisted service users in creating their profiles such as time required, access to equipment and how they could ensure the service users were providing informed consent. However, the positives of the project were generally seen to outweigh the negatives: staff noted the service users enjoyed creating the profiles and that it had helped them to have a better understanding of how the service user communicates and their needs (Cavet & Grove, 2005). Staff reported only positive outcomes for the service users with no adverse effects. All participants benefited from improved staff knowledge of their needs and preferences, the majority of participants also benefited from improved communication with staff and from the additional activity that creating the profile allowed them.

In the MENCAP project, videos were made of sporadic events that took place with staff estimating that they spent on average 30mins a week profiling (Cavet & Grove, 2005). These videos provided new perspectives for those who are making decisions on behalf of the service users and gave the service user more self autonomy, allowing them to have a say in decisions affecting them. The success in this initial study has contributed towards Project Apple, which helps young adults withSevere Speech and Physical Impairments and other disabilities to create personal profiles incorporating multimedia, which are then used as a form of self advocacy when decisions regarding their futures are being made.

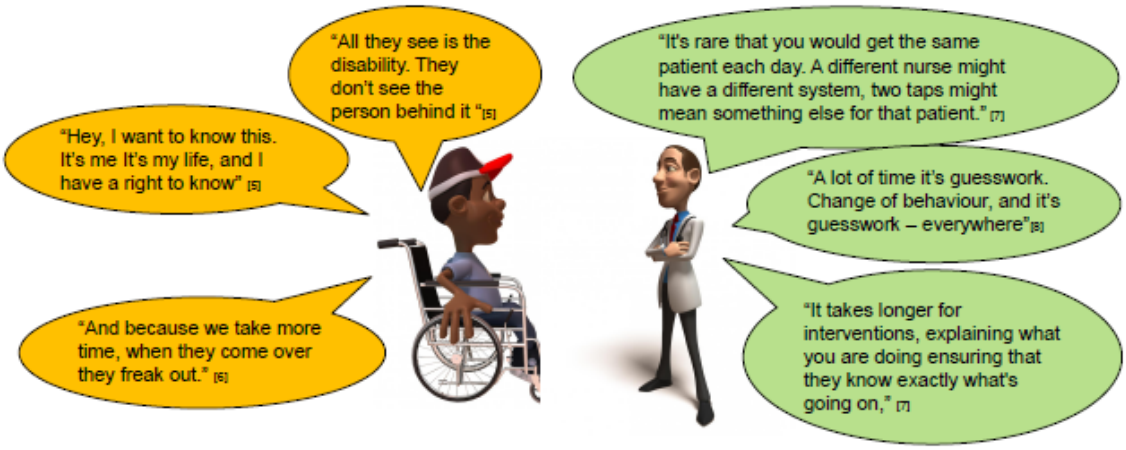
Facilitating communication of people with complex communication needs in hospital: A review of the literature

Suzanne Prior BSc , Kathleen Cummins MA, Annalu Waller PhD, Thilo Kroll PhD, Sue Balandin PhD

Did You Know?

- There are between 1.5 and 2.5 million people in the United Kingdom with a Complex Communication Need (CCN) [1]
- 600,000 people in the UK are unable to communicate basic yes/no choices. [1]
- Young adults with CCN are 10.6 times more likely to be admitted into hospital than their peers [2]
- Adults with lifelong disabilities have more health problems [3]
- People with CCN are at a higher risk of having illnesses which go undiagnosed or untreated [4].

Problems for patients with CCN in Hospital



Solutions From The Literature

	Information Interventions	Equipment Interventions	Training Interventions
Current Interventions	Detailed shift handover [7]		Persevering with communication [7, 9] Getting assistance from family [7]
Suggested Interventions	To identify patients with CCN on admission [10] To improve the flow of information [9, 10]	Inclusion of AAC devices on the ward [6]	Training for nurses [7, 9]

Current Research Projects at The University of Dundee

CHAMPION

The CHAMPION Project aims to use existing work done in multimedia [11,12] as a means of advocacy for people with CCN and to look at how best to incorporate these multimedia information profiles in a patient's existing Electronic Medical Record.
This project is user centred, involving patients, their care workers and medical staff as stakeholders in the design and evaluation of the system.

TEAACH

The TEAACH project aims to study the barriers and solutions to successful communication between patients with little or no functional speech and the nurses who care for them, and to develop a training module to overcome these communication barriers.
This project is user centred, involving patients, their care workers and medical staff as stakeholders in the design and evaluation of the module.

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Appendix C. Focus Groups as a Requirements Gathering Method with Adults with Severe Speech and Physical Impairments

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Focus Groups as a Requirements Gathering Method with Adults with Severe Speech and Physical Impairments

Technological supports have the potential to greatly improve the quality of life and independence of adults with Severe Speech and Physical Impairments (SSPI). In particular, Augmentative and Alternative Communication (AAC) devices can enable people with little or no speech to communicate with others. However, the rate of rejection of AAC devices is estimated to be as high as 53.3%. It is suggested that a major reason for this rejection is a lack of user centred design in the development of these devices. As part of a wider study looking at involving adults with SSPI in all stages of user centred design, this paper looks at the use of focus groups in requirements gathering with this user group.

Keywords: Disability, usability, inclusive design, accessibility, focus groups

INTRODUCTION

People with disabilities have frequently been excluded from both quantitative and qualitative research studies. Awareness is growing of how this quite heterogeneous group can be involved in and contribute to research (Oliver, 2002). One method used in HCI to gather opinions from potential users of a piece of technology is through focus groups. Focus groups can be used at any stage of the development process, to gather

requirements for a piece of technology, to comment on design ideas or to discuss the product following evaluations.

Focus Groups

Focus groups have been used as a method of market research since the 1920s; they have been used in wider research since the 1950s when ‘focused interviews’ were developed to uncover people’s feelings and reactions to the propaganda used in the previous decade as part of the war effort (cited in Kitzinger, 1994). Focus groups are now used as a means of evaluating the experiences of people with health and social services and in action research projects (Kitzinger, 1994, Willson et al., 2005). Focus groups are also commonly used in requirements gathering to identify the requirements from different groups of people and discuss any conflicting wishes in the design. In Joint Application Development, focus groups are routinely used, and are very structured and prescribed (Sharp et al., 2007). Focus groups can be used at any stage of the development cycle; Kurniawan (2006) used them before the design and development had taken place or even been planned in order to uncover why older adults were reluctant to use existing mobile phone technology, whereas Kim (Ryoung et al., 2009, Murphy et al., 2000) used them at the design stage. The same advantages that apply to the use of focus groups in social science can apply when used in HCI.

Focus groups are useful in gathering many different views on a topic and insights into people’s shared and different opinions (Gibbs, 1997). In a focus group the discussion between participants and sharing of views may lead to a greater disclosure and volunteering of information; it also allows a researcher (or designer) to discover why a participant holds a certain view (Gibbs, 1997). Participants may be encouraged or

reminded of something they wish to share as they piggyback on each other's statements (Rennekamp and Nall, 2000).

A session will typically last 2 hours with a facilitator asking questions and encouraging people in their group. Traditional focus groups are composed of 4-8 participants who might have different opinions on an issue and will discuss these opinions during the course of the session; the other important feature of a traditional focus group is the moderator who will ensure that the group maintains the focus on the topic. Participants will usually sit in a circle or around a table.

Kitzinger (1994) states that focus groups should take their results from analysis of the interaction between participants and how they respond to the statements made by one another. This interaction allows the participants to explore other points of view and it is these differing points of view which provide a researcher with an overview of the issues and feelings surrounding the aspect under investigation (Cameron, 2005).

Focus groups are now becoming more common in HCI as can be seen by recent panels and workshops at conferences such as ACM CHI (Rosenbaum et al., 2002).

Severe speech and physical impairments(SSPI)

Communication impairment can be congenital (e.g. due to cerebral palsy) or acquired (as the result a brain or spinal injury from a car crash or stroke). Individuals may experience a physical inability to speak or be unable formulate the words needed for communication. Additional sensory, intellectual and/or language impairment, e.g. hearing impairment, aphasia or developmental delay, may also result in difficulties in cognitive processing and receptive communication.

Augmentative and Alternative Communication (AAC) is the general term for the methods used to aid communication by those for whom the usual form of communication through speech is not sufficient. AAC can be divided into the two different categories of unaided and aided. Most people who use AAC will use a combination of both (American Speech-Language-Hearing Association, 2002).

In unaided AAC systems, e.g., sign language, Makaton (Communication Matters, 2008) and facial expressions (Communication Matters, 2003), additional equipment is not used. These systems have the benefit that they can be used anywhere and the user does not need to carry additional equipment around. However unaided AAC has the disadvantage that the communication partner needs to understand how the system works.

Aided AAC systems refer to communication methods that involve a device – this may be electronic or paper based (e.g. a word board) – which is external to the user. Electronic AAC devices usually provide access to written or spoken output. Depending on the level of physical impairment, physical access to such technology may be restricted to one switch input.

Use of Computers by people with SSPI

The number of computer users with cognitive and developmental disabilities is increasing (Clayton, 2006); day and residential units provide computer courses as part of the program for service users (Parsons et al., 2006) and schools for children with disabilities have computer lessons in their basic curriculum (Judge, 2001). In addition, as adults with developmental disabilities become more integrated into the workplace, the demand for computer software which is accessible by a wider spectrum of users is likely to increase.

Although individuals with cognitive and developmental disabilities use general ICT, the main use of technology by this user group tends to be in assistive technology and AAC devices. However, there is a high rate of abandonment of AAC devices estimated at 33% (Johnson et al., 2006)The main reasons given for abandonment or rejection of assistive technology are a lack of training for the end user and a lack of flexibility in adapting the system for the individual. Other reasons reported include a lack of confidence on the part of the user in their ability to use the system and the prohibitive costs in learning how to use the system.

It has also been suggested that a lack of user centred design may contribute to the poor adoption of technology and that the inclusion of end users in the design process may reduce this abandonment rate (Waller et al., 2005a)**.**

Initiatives, such as Inclusive Design (Newell and Gregor, 2000) (the development of items to be as usable as possible for as wide a group as possible), promote consideration of these groups in design. This move presents significant challenges to researchers including difficulties in obtaining informed consent, meeting the needs of different user groups and finding ways of communicating with the users in order to gain their requirements (Newell and Gregor, 2000). However, while there is literature on developing user centred design methods for older users who may have age-related disabilities, there is little research into developing user centred design methodologies for adults with SSPI with their varied physical needs and possible cognitive impairment (Waller et al., 2005a).

The aim of the CHAMPION project is to investigate ways of conducting user centred design with adults with SSPI. In order to do this, existing methods in user centred design were examined for their suitability to be used with this user group and where necessary

the methods were adapted to make them more suitable. One such method which is used by designers and developers in user centred design is focus groups.

Focus Groups with SSPI

Given that adults with SSPI have traditionally been excluded from software design and have limited experience of technology and of designing technology (Waller et al., 2005b), it would seem sensible to conduct focus groups with them when gathering requirements or evaluating design solutions. Focus groups could potentially empower these adults to offer critical feedback on requirements and design.

However a structured review of the literature using thesaurus terms for communication impairment and speech disability resulted in no mention of conducting focus groups with adults with SSPI within the software engineering process. A structured approach to searching the electronic databases, Medline, CINAHL, PsycInfo and Web of Science was used, involving Boolean combinations of free text word, indexed keyword and thesaurus terms for focus group methodology and communication impairment and speech disability. Following this an author search on recovered papers was conducted.

Inclusion criteria for this structured review were: (a) published in a peer reviewed journal between 1990-2009; (b) published in English; (c) included focus group used as the primary or one of the principal research methods; and (d) involved participants with SSPI. Excluded from the review were articles which incorporated focus groups as part of a larger process but did not report on the focus groups themselves.

Twelve (12) papers discuss holding focus groups with adults with SSPI, but these studies are restricted to the medical and social sciences fields.

The literature review shows that the use of focus group methodology with participants with SSPI has increased since 1999, prior to which there were no reports of any focus groups being conducted with participants with SSPI (Schlosser, 1999). At present there is no best practice for focus groups with participants with SSPI, with researchers altering traditional focus group methodology as per their individual research requirements.

The review also suggests that current focus group methodologies are not suitable for studies which aim to gather the views of a wide variety of participants with SSPI. Adaptations have been used in face to face focus groups through Talking Mats (Murphy, 2006) where participants are asked to place images related to topics under discussion in one of three groups to show whether they are happy, unhappy or indifferent to the topic. The impact this adaptation makes on the amount of conversation and the number of questions asked by participants is not reported.

Other adaptations that could be made to traditional focus groups to promote discussion between participants with SSPI might include providing questions ahead of time in order that participants with AAC devices could prepare longer answers in advance, and showing questions on a screen in the room in a symbol format that participants understand. This may help to include more participants with SSPI and intellectual disabilities; to date many focus groups with participants with SSPI have focused on participants at the upper end of the intellectual spectrum (e.g. Rackensperger et al., 2005, McNaughton et al., 2002a, McNaughton et al., 2006).

Online focus groups were used in 5 (42%) of the papers in the review. Online focus groups are able to solve many of the problems faced in holding traditional focus groups with participants with SSPI, such as the stress placed on participants to produce replies quickly with their AAC device and the ability to include participants from a wide

geographical area. This is particularly important when the pool of potential participants is small (McNaughton et al., 2002a, McNaughton et al., 2001a, McNaughton et al., 2006). However online focus groups are not without their own problems, holding the focus group online requires that participants are literate, able to produce messages in written form and comfortable in using the internet. Typically in online focus groups participants must also be willing to take part in the focus group over an extended period of time.

To date no focus groups have included a moderator with SSPI in face to face focus groups. The papers in this literature review made no reference to any training or preparation work done with moderators in preparing them for conducting a focus group with adults with SSPI. This may be due to the fact that the vast majority of moderators had experience as either speech pathologists in the past or had done extensive research previously with adults with SSPI. If a training program was available for all researchers in holding focus groups for adults with SSPI, it is possible that more researchers may feel confident in conducting these groups.

The analysis of focus groups, should not focus merely on the information provided by the participants to a set of questions, but should also concentrate on the interaction between participants and non verbal expressions and cues given from them (Catterall and Maclaran, 1997). All of the papers in this review used content themes (examination of transcript for recurring themes) as a means of analysis, but only 4 (33%) of the papers looked at the interaction between participants. Given the limited opportunities adults with SSPI may have for interaction with others the analysis of these aspects could provide useful insights to researchers into the participants' views and opinions.

Only one paper involved anyone with SSPI in the reporting of the focus group (Rackensperger et al., 2005) when they were included within the research group. With

conferences such as International Society for Augmentative and Alternative Communication (Larraz and Escoin (eds), 2010) now not only being accessible to adults with SSPI and other disabilities, but proactively encouraging their participation, there is now the opportunity for adults with SSPI to take an active role in the dissemination of findings.

Extra Considerations When Planning Focus Groups with Participants with SSPI

After an examination of the current state of the field for focus groups with adults with SSPI and in light of the lack of guidelines available, an examination of the general additional considerations when working with adults with SSPI was conducted.

Communication Considerations

People who use an AAC device for communication may produce words up to 25 times slower than those with normal verbal speech (Higginbotham et al., 2008a). The time therefore for a participant to reply, for example "Yes, that has happened to me" could take up to 2 minutes for a participant relying on AAC (Rate Enhancement, 2009). Another problem may exist when participants have a low tech AAC aid for which a facilitator is required to follow the participant's finger pointing and speak the message on their behalf. A participant with dysarthric speech may be able to produce words at the same rate as a participant without a SSPI; however the need for clarification of the response can slow down the rate at which the response is understood by the group (Hustad, 2006b).

Cognitive Considerations

It is a common misconception that people with SSPI will also automatically have a learning disability. This is not the case, while it is true that some will have a learning

disability which can range from mild to severe. However, it is important to consider the effect a participant's learning disability may have on their ability to participate in a focus group.

Literacy Levels

One issue concerning a participant's learning disability or cognitive impairment is the process of informed consent. Terms in consent forms and participant information sheets may contain technical and/or experimental terms or jargon which is unfamiliar to those without experience of participating in research projects (Dickinson et al., 2007), and confusing to those with a lower rate of literacy than those who traditionally participate in research projects, such as students.

Participants may be asked to take their own notes on certain discussions or be given 'prompts' to help with the discussion. It may be necessary to consider what if any prompts can be used with participants with SSPI.

Concentration Span

The other area of focus groups in which a participant's learning disability may have an effect is their ability to understand all that is being said in the conversation and the moderator's questions. A focus group typically will have a steady flow of conversation, argument and topic change (Krueger and Casey, 2009); this type of conversation may be difficult to follow for those with SSPI.

Physical Considerations

Focus Groups have traditionally been conducted around a table (Kruegar and Casey, 2009), with a moderator at one end of the table and possibly a moderator's assistant at the other who has the role of taking notes Participants with cerebral palsy, a common

cause of SSPI, are likely to have a range of motor impairments which may restrict their ability to sit at the table and/or may require them to use a wheelchair (Finnie and Bavin, 1997). As a focus group is primarily a study of the interaction between participants (Morgan and Krueger, 1993), the layout of a group requires careful consideration to ensure that participants are positioned in a way that encourages conversation and debate.

People with cerebral palsy are likely to become tired more quickly than the general population (Jahnsen et al., 2003b). This is attributed to "post-impairment syndrome", which means that those with cerebral palsy will use between 3 and 5 times as much energy as those without the condition (Wood et al., 2008). Fatigue is also one of the most common and debilitating symptoms associated with acquired brain injury. The average length of a focus group is between 90mins to 2 hours (Kruegar and Casey, 2009, Kitzinger, 1995); this is likely to be too long for participants with SSPI.

These difficulties should not, however be seen as a reason to exclude those with learning disabilities from participation in research (Mactavish et al., 1998).

Diversity

A commonly used term in focus group research is "purposive sampling". Purposive sampling can be defined as "*a procedure by which researchers select a subject or subjects based on predetermined criteria about the extent to which the selected subjects could contribute to the research study."*(Vaughn et al., 1996 p. 58). While people with SSPI will have some experiences in common which a researcher may want to delve into and discuss, people with SSPI are still a diverse group of participants. It may be that more specific requirements than simply having a SSPI are required for participants in the group, such as in studies investigating the employment experiences of adults who use AAC (McNaughton et al., 2006, McNaughton et al., 2001b, McNaughton et al., 2002b).

This can then make recruitment of participants more difficult and may require looking at a broader geographical region.

Experimental Design and Methodology

Participants

For this pilot study, AAC users who were capable of giving informed consent using a modified consent process (see Table 1) and who received services at a resource centre either as day service users or residents were potential participants. Participants were recruited through the Communication Support Worker at the resource centre.

10.5.1. Focus group composition

Six participants (3 female and 3 male) took part in the focus group. Their age ranged from 25 to 55**.** Five of the participants attended the resource centre as day service users; one was a resident service user.

Preparation of the Focus Group

The focus group was held in the resource centre in a room used for activity sessions. As all of the participants used motorized wheelchairs a semi-circle was formed with facilitators placed next to the participants who required the most help with their communication. The moderator sat at the top of the semi circle with the video recorder placed to the left of the moderator to ensure all the participants were in view (see Figure 1). One participant had a hearing difficulty in addition to his speech impairment so a facilitator was sat next to him at an angle to allow for better communication of the questions and to assist with signing of questions.

The video camera was able to rotate and was operated by an assistant. The session was video recorded to capture the non verbal behaviour, which is often a primary means of communicating for participants with SSPI.

Obtaining Consent

As the adults with SSPI were unlikely to be able to consent through traditional channels (e.g. giving participants an information sheet to read and then asking them to sign a consent form), the protocol described in Balandin, Berg et al., (2006), was followed.

Participants were asked a series of multiple choice questions to which they could answer yes or no such as "Can you withdraw at any point?" to ensure they had understood their rights in the study, see Table 1.

Assistants in the Focus Group

In addition to the participants and the principal moderator, a moderator's assistant to assist in note taking, two facilitators to aid in communication with the participants and a further assistant who operated the video camera were present.

Length of Session

Due of the increased chances of fatigue the session only lasted 1 hour, participants were told they could take a rest or leave at any time. During the session, one participant chose to leave for 20 minutes and returned before the end of the session.

Questions

The number of questions in the session was significantly less than the usual number of questions that would be set in a focus group. A focus group with participants without disabilities could expect to devote 10 minutes to crucial questions (Kruegar and Casey,

2009), giving the potential for 6 questions an hour. In this session only 3 questions were covered.

This was for two reasons, to reduce the cognitive demands of participants and to allow participants longer to prepare their answers.

The moderator took care to ensure that the participants did not interrupt each other, and allowed one participant to complete what they were saying before starting their own reply, this intervention was only required once during the session. The participants were very patient in waiting for each other to either prepare an answer on an AAC device or to have their reply confirmed by a facilitator.

Obtaining Feedback

Frequently in focus groups, a written summary or even the full transcript will be provided to participants after the focus group session (Hemsley et al., 2008c, Hemsley et al., 2007). Given that the participants had varying levels of literacy the feedback was provided orally at the end of the session by the moderator's assistant. This feedback served two functions; firstly to ensure that the note taker had captured the main topics of conversation and secondly to act as an affirmation to the participants that their views had been listened to.

Results of Session

Requirements Gathered

At the start of the session participants were reluctant to offer many suggestions but after some initial encouragement, were keen to provide a variety of requirements regarding how they would interact with the computer system, what support they would need and how they would expect the system to respond to the interaction. Participants were also very good at considering how other users and people at the centre with different needs

would use the system. The participants provided 7 significant requirements related to the functions of the system and 4 significant requirements related to the design of the interface.

Participants Response to Session

Participants were initially hesitant in answering questions and initially only gave short answers in reply to a direct question. After the first 18 minutes participants began to directly engage with each other with only minimum input from the moderator to move onto the next question or to bring the conversation back on topic.

The time spent on each question increased during the session from an initial 3 minutes on the first question to a peak of 26 minutes on the third question.

An examination of the transcript shows that 47% (n = 43) of the utterances by participants were unprompted and that all participants responded unprompted at least once. For two participants, the number of unprompted responses outnumbered their prompted responses. The other interesting result from the transcript is that the 3 participants who responded the most were the 3 with the most severe physical and speech impairments.

There were 9 significant pieces of information for the requirements of the system provided during the course of the focus group.

The feedback section of the focus group was the most animated of the hour with participants agreeing both vocally and with nodding of the head that the account was accurate. The summary section of the session finished with one participant saying "*One last thing, thank you for listening"*.

Discussion

The results of this pilot study show that a focus group can be run with individuals with SSPI if the necessary planning steps are taken.

For the focus group to be successful, careful thought and consideration should be given to the planning of the session. It may be useful for the moderator to have more prior information on the needs and backgrounds of participants than is usually used in focus groups where the moderator may only know the age, gender and qualifying features of the participant to the topic under discussion. This will enable the research team to make better plans and preparation for the session.

Unlike traditional focus groups where a moderator may act alone, or with the help of one assistant, holding a focus group with adults with severe speech and physical impairments and other disabilities requires a team approach. Ideally all of those on the research team would be experienced in working with people with SSPI. Where this is not possible, at the very minimum the facilitators need to have experience in the field, ideally with those who they are facilitating in the group.

The location for the focus group needs to be visited before the session, ideally several days in advance. This visit allows those organising the focus group to check that the room is suitable and accessible for the participants. The visit can also assist the video operator to find the best position for a video camera to be placed in order to capture all the participants at once, and if this is not possible to make arrangements for a rotational stand for the camera to sit.

As with all focus groups, careful consideration of the questions is needed to help with a successful and productive focus group (Kruegar and Casey, 2009). It is important that the researcher ensures that the questions are both simple enough for the participants to understand and answer and that they do not lead participants unconsciously to any one

answer. It may also be helpful for participants to be given the questions in advance of the focus group session, this can be particularly helpful to those participants who use AAC devices and may allow those with some devices to prepare and store responses and experiences ahead of time.

Another method for increasing the production rates of conversation would be to allow participants to prepare answers simultaneously rather than waiting for one participant to complete their response before continuing the conversation. This would be likely to speed up the production of conversation but would possibly diminish the amount of interaction between participants. In an audience situation this technique could be useful where a speaker is looking for individual responses, but when using a focus group the interactions between participants and how they respond to each other's comments is valuable data. Experts on focus groups suggest that one of the defining features of a focus group which differentiates it from a group interview is the examination of the interaction between participants (Kitzinger, 1994). During the focus group session, the participants with SSPI were able to interact with each other and many of the ideas that they generated emerged as a result of discussion with and suggestions by other participants. Often one participant would share a story relating to an experience and this would prompt another to think of a similar story or offer suggestions on how a piece of technology could have helped them there.

Conclusion

There is now a growing awareness of the value in including participants with disabilities in research around technology which both may have an effect on interventions for people with that disability and also in research involving the general population.

Participants with SSPI may have a range of other disabilities that have the potential to impact on their ability to participate in a focus group, however with proper planning and consideration the impact of these disabilities can be reduced.

The use of participants with SSPI in focus groups is still a new approach and as yet no best practice exists; this work builds on existing research involving participants with SSPI as focus group participants and offers suggestions for those considering conducting focus groups involving adults with SSPI.

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Appendix D. Forum Production and Script

Accepted for presentation at the International Society for Augmentative and Alternative Communication Conference, Barcelona, July 2010

Including Adults with Severe Speech and Physical Impairments as Actors in Forum Theatre

Prior, Suzanne; Waller, Annalu; Kroll, Thilo; Morgan, Maggie; Cummins, Kathleen

INTRODUCTION

Forum theatre was developed by Boal in Brazil and is described in his book "Theatre of the Oppressed" (Boal, 2000). Boal originally intended forum theatre to be used by oppressed and marginalised groups to allow them to provide their views and/or influence political change; since its beginning in the 1970s forum theatre has been adapted for different purposes (Newell et al., 2006c).

Newell et al (Newell et al., 2006b) suggested that forum theatre could be used in facilitating discussion between users of AAC devices and clinicians or designers. Given the potential for forum theatre to be used as a means of promoting interests and needs of marginalised groups, it is perhaps surprising that to date no published papers report it being used for either scenarios dealing with situations faced by adults with Severe Speech and Physical Impairments or with actors who have Severe Speech and Physical Impairments (SSPI).

As part of a wider project (Prior et al., 2009, Blackstone, 2009) looking into issues surrounding adults with SSPI and their experiences in hospital, forum theatre was used to elicit requirements for an electronic multimedia profile. This paper describes the experiences of those involved in the process including two amateur actors with SSPI.

Ethical approval for this study was obtained from the organisations involved in recruitment and from National Health Service (NHS) Tayside Ethics Committee.

PROCESS

Script writing: Two adults with SSPI from a day and residential centre were recruited to act the role of patients in two specially commissioned scenarios. In keeping with previous work which used forum theatre for requirements gathering, a professional script writer was employed to develop a story, write the script and direct the actors in rehearsals (Carmichael et al., 2005, Newell et al., 2006c). Unlike previous work where scripts have been based upon the researchers' ideas of situations where a potential piece of technology could be used, the scripts in this study were based on stories told in a focus group with adults with SSPI (Prior et al., In Prep). Participants in the focus group discussed problems they had personally faced in hospital as a result of communication breaking down between themselves and medical professionals. These stories, together with others reported in the literature (Hemsley et al., 2008a), formed the kernels of two scripts. Several iterations of the script were produced and were modified in light of feedback from experienced medical staff and researchers.

Rehearsal: A single day's rehearsal would normally suffice for the preparation of the performance of two short scripts. However, three days were spent in rehearsal as amateur actors were playing the parts of patients. The two amateur actors took turns to rehearse with the professional actors in order to allow them time to rest between sessions. To reduce fatigue on the parts of the amateur actors, rehearsals took place at the residential centre. A support

worker was also present during rehearsals to assist with communication and to provide personal care.
As with other plays with nonspeaking roles, e.g., Operation Elvis (Taylor, 1983), the script writer had used prose to provide directions for the actors. Dialogue was stored in voice output communication aids where appropriate. It soon became apparent that the actors with SSPI required spoken dialogue even if their speech was unintelligible. The scripts were rewritten for day two to include dialogue for all characters.

In forum theatre questions may be asked of the actors 'in character'. An afternoon of rehearsals was spent preparing the amateur actors for this. Background stories for each character were discussed until the actors were confident they would be able to improvise for the majority of questions asked of them.

Performance: The audience for the performance was consisted of junior doctors who were attending the session as part of a disability awareness lecture. A brief introduction to the performance was given prior to the first scenario, but no specific information on content was given. After the first scenario a trained facilitator invited comments from the audience on how they felt upon seeing the scenario and what their impressions were on how each character behaved. The audience had the opportunity to ask questions of the characters on why they acted the way they had and how they felt in the situation.

REFLECTIONS ON THE EXPERIENCE
Amateur Actors' Experience: Both amateur actors with SSPI grew in confidence during the rehearsals. They were able to voice their opinions and engage in lively discussions with the researchers and the two professional actors. Both enjoyed the experience and one is now exploring further theatre work as part of training for new support workers. The amateur actors noted the significance of what they were doing. One reflected that:
"I think it will be good for the doctors to see someone like me using a talker and being in a play"
Professional Actors' Experiences: The two professional actors were initially nervous at working with the adults with SSPI. They quickly became confident in working with the two amateur actors and other adults with SSPI in the residential centre. One actor described the experience:
"*I had no idea what to expect at all. On arrival to day one of rehearsals, I was really anxious ... and thought the process would be a nightmare. It was a completely different story as we had a fantastic rehearsal atmosphere and really got on with the task of producing the two scenes."*
Medical Trainer: The disability awareness session for the doctors was organised by a learning disability nurse. The nurse had not met any of the actors or researchers prior to the session but had been informed of the focus for it. The nurse reflected on the experience of watching the session:
"The performances were wonderful; they really got the message across about communicating with people. I felt that it could be used as a session about how to communicate with people , as you could have had a great discussion going"
The nurse did note that the doctors may have benefited from more information on strategies for communicating with adults with SSPI and this has been noted for future work.

DISCUSSION

The process of including adults with SSPI in acting for a forum theatre session is time consuming and requires careful planning by those wishing to undertake it. The time taken for rehearsals in this instance was three times that of usually needed when working with professional actors without disabilities. The resources required to facilitate full participation were also increased as support staff was required.

The involvement of adults with SSPI in scenarios featuring characters with SSPI has many advantages. First, it is unlikely that a professional actor could realistically portray a character with SSPI. Second, the actor with SSPI is able to provide more believable feedback to the audience when questions are posed to them in character. Finally it is in keeping with the "nothing about us without us" manifesto (Oliver, 2002) to involve adults with disabilities in research that has the potential to have an impact on their lives.

CONCLUSION

Despite the difficulties and extra work involved in the preparation of the forum theatre sessions with adults with SSPI, the researchers involved feel the process would not have been as beneficial or as insightful without the help of the two amateur actors with SSPI. We recommend the use of forum theatre for facilitating discussion between service users with SSPI and professionals who may work with them.

ACKNOWLEDGEMENTS

This work is part of a doctoral study funded by Capability Scotland. We thank the actors, support staff and colleagues who participated in the project.

Scripts

SCENARIO 1 – " A shame, eh?"

Scene – '*hospital ward'. A bed, made up, with female patient, Maria, in it. She could be clutching an oxygen mask (?) Her eyes are initially closed but once dialogue starts, her eyes open.*

Enter consultant(female) and FY1 (male).

C – (*picking up notes*)
Right Dr Jones, would you like to present your patient.

FY1- Yes, this is Maria Russell. Brought in yesterday. She has double pneumonia. Cerebral palsied, non-speaking, can't communicate.

C- Sad case. What is your suggested plan?

FY1 - I was about to prescribe ceftriaxone?

C - That can have some unpleasant side effects and in a case like this....have you considered palliative care?

(*Nods to side of stage)*

C - (*To Maria*) We'll come back in a bit

C and FY1 move to other side of stage

FY1 - Palliative care? There's no actual morbidity? (*check terms with medics*)

C - No, but in this type of case……you know….what's the point? It just prolongs suffering. A blessed release.

By this time MR is beginning to react with noise and movement.

FY1 - She's (*checks notes*) only thirty-five, that's quite young?

C - Yes…but I mean....what sort of life?.....

C responds to MR's now frantic shouts and movements

C - There, there. Don't you worry. We're looking after you.

MR gets even more frantic

FY1 - Can she hear us?

C - Probably not. Even if she can, she would not understand.

FY1 looks a little doubtful and unsure.

FY1 - Ah! That's my pager!

Takes pager/mobile out of pocket and looks at it)

Would it be alright with you if I go, I've been waiting on these test results. May I catch you up later?

C - Fine.

Exit FY1 in a hurry.
MR is now very distressed, breathless and possible coughing.

C - There, there! Don't you upset yourself. You're quite safe.
I think we'd better give you something to calm you down.
Nurse!

PAUSE

Thinks bubble for Consultant, Maria and then FY1.

(As soon as thinks bubbles over, FY1 exits to change)

Go from thinks bubbles to general discussion about what assumptions are being made. Remind audience that AAC device was taken away when she arrived and she was feeling too ill to make too much of a fuss.

Scene 2 – *Consultant is standing by the bed, trying to calm MR. He calls for the nurse again.*

Enter Peter Russell, Maria's husband.

PR Hi Maria! How are you?

C And you are..?

PR I'm Maria's husband.

C Oh.

PR (*to Maria*) Where's your talking device?

Maria manages to point off

PR They've not taken it off you?!

Maria nods

PR Oh, for God's sake!

C Maria is very distressed. I think you need to calm down.

By now, Maria has stretched out an arm, Peter has taken her hand and sat down on the bed. Maria is much calmer!

PR (*looks at MR*) What's going on?
Don't worry, sweetheart. I took Jessica to your mother's, she's quite happy. Wants to come and see you but I said the doctors had to give you your medicine first.
I've rung work – so they know you won't be in for a while!

You are looking a bit rough.

(*To consultant*) You've started treatment.

C Er…not quite yet.

PR But the GP said she's got pneumonia. That's an antibiotic job, isn't it? You do know she's allergic to penicillin don't you?

C Er – well – yes. But we do need to.make an individual assessment for each patient. I've just now completed my assessment, and I'm going to sort out the medication right now..

PAUSE

SCENARIO 2 – Who' s the Expert?

Scene – *A hospital waiting room. Tony Lynley, a 45-=year-old man with CP, is seated on one of the chairs. He has on a hospital gown, covered by a dressing gown.*
(Perhps we can mange just with the dressing gown?)
He has an AAC device with him.
Possibly a nurse is sorting forms etc at a nearby table. In which case –

NURSE Mr Lynley?

Tony nods

NURSE Would you like me to look after that for you? While you have your scan?

TONY When I go in.

NURSE Oh! That's what it's for.
OK. Give it to me then.

Nurse goes back to her table.
Enter Doctor Jessop. He has a good look at Tony, goes to the desk.

DOCTOR The patient's notes?

The nurse passes him the notes, which he scans very briefly.

DOCTOR *(To Nurse)* This is ridiculous! How on earth can I put him through a scan?

(To Tony) Can you stay still?

Tony shakes his head.

DOCTOR *(To Nurse)* Then this is a waste of my time!
Who on earth referred him? His GP?

Doctor checks notes again

DOCTOR The orthopaedic department?
What do they think they're playing at?

(To Tony, very loudly, as if T is deaf/stupid) I'm sorry, you'll have to go home! We can't do the scan if you can't stay still! Do you understand me?

(*To nurse*) Can you sort him out, get his transport back, whatever?

Doctor puts notes back on table and begins to exit

Meantime Tony has been fiddling with his AAC, to produce a message he has produced earlier.

TONY ***(via AAC)***
Last time I did this, I had an epidural. That relaxed me enough time to give me the scan.

Doctor does a 'double-take'.

DOCTOR What?!

TONY plays message again. Tony is looking pretty cross.

DOCTOR *(visible pause)* Right! That's what we'll do!

Goes back to table, picks up notes and prepares to write in them.

DOCTOR It would have been helpful if ---- ah------ I see.

Right!
We'll fix another appointment and arrange for an epidural.

Tony looks fed up at the delay.

DOCTOR We'll fit you in as soon as possible.
Nurse, make sure he's put on the cancellation list, will you?

PAUSE

Appendix E. Participatory Design of a Talking Photo Album

Paper presented at the 2010 RaATE Conference, Coventry UK

The Participatory Design of a Talking Photo Album for Adults with Severe Speech and Physical Impairments

S. Prior, H.Betzler, A.Waller

Communication is an essential part of life and an important part of communication is the ability to tell stories. These stories can include every day events up to momentous life occasions. Through stories people build relationships, learn new information and can argue their point of view. However, people with Severe Speech and Physical Impairments (SSPI) cannot access their stories easily. At present voice output communication aids are not suited to sharing stories; it is difficult to create a story, store it, retrieve it and narrate it (Waller 2006). People with SSPI often rely upon a carer to enter stories into the device, but this is time consuming and results in static, monologue output as the story text tends to be stored under a single key. Another way of sharing stories is through photographs, with some use being made of "speaking photograph albums"; allowing voice recordings to be linked to individual photographs. However, non-speaking individuals still have to rely on speaking helpers and the playback still mimics a monologue.

The problems surrounding the "talking photograph album" were addressed within a participatory design project which is investigating ways to include people with SSPI in the design of technology.. The project followed participatory design guidelines being developed at the School of Computing at the University of Dundee (Prior 2010).

Six adults with SSPI and a support worker were enabled to participate in all stages of the design using innovative design methods; these included magnetic white boards, etran boards and PowerPoint designs.. Participants were initially invited to choose the focus of the project; they expressed a desire to share their stories and their photographs but indicated that they currently require assistance in doing this. The participants then helped design the software from low level paper based designs through to a fully working piece of software.

Appendix F. Dissertation on Development of Talking PhotoAlbum

School of Computing

Participation of People with Complex Communication Needs in Designing Assistive Technology Software for Information Sharing

Author: Heike Betzler

Degree: MSc in Applied Computing, University of Dundee, UK

Supervisor: Dr Annalu Waller

Date: 28st March 2011

Executive Summary

Communication is vital - not only to express wants and needs, but also to build relationships and to share experiences. People with Complex Communication Needs (CCN) have difficulty in sharing life-experiences.

The aim of this master project was to develop a software application for and with people with CCN that would allow them to share information.

Eight adult participants with CCN chose photos to share experiences. Using participatory design methods, they provided requirements and helped to design The Talking Photo Album. Prototypes were evaluated at each stage of the development process. The final version was developed in C#, runs on a portable touch-screen computer and includes a database to manage the photos and their descriptions.

The resulting software will be provided to the participants and used by a learning disability centre with adults with CCN.

Declaration:

"I declare that the special study described in this dissertation has been carried out and the dissertation composed by me, and that the dissertation has not been accepted in fulfilment of the requirements of any other degree or professional qualification."

……

Heike Betzler

Certification:

"I certify that Heike Betzler has satisfied the conditions of the Ordinance and Regulations and is qualified to submit this dissertation in application for the degree of Master of Science."

……

Dr Annalu Waller (Supervisor)

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First of all, I would like to thank my supervisor Dr Annalu Waller for her affirmatory and inspirational guidance throughout the project, which created a very positive and enjoyable work environment. Furthermore, I would like to thank her and her team for making me feel part of the gang. Particular thanks to Suzanne Prior who always lent me an ear.

I would like to thank all the participants for their excellent contributions to my study, I enjoyed working with you. Particular thanks to Bernadette Brophy-Arnott who put me in contact with the participants and who helped to arrange the user sessions.

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1 Introduction

Assistive technology (AT) devices are anything that helps individuals with disabilities to maintain or increase their functional capabilities regardless of whether the device is commercially bought or self-made (U. S. House of Representatives, 2010). The World Health Organisation (2004) defines AT as “an umbrella term for any device or system that allows individuals to perform tasks they would otherwise be unable to do or increases the ease and safety with which tasks can be performed.” In the UK, the term is understood slightly different. In contrast to the former definitions, the focus is on the independence that the individual gains though the use of AT (King's Fund, 2001).

One category of AT devices is communication aids. These help people with speech disabilities to communicate. At first sight, speech output devices seem to be liberating for people with Complex Communication Needs (CCN) as they allow the users to be heard and understood. However, not everyone with CCN is pleased with their communication device, whether it is because the device visibly singles them out from others, whether the learning effort required is too high or the devices available are just not very user-friendly. All might be explanations for abandonment rates of augmentative and alternative communication (AAC) devices reported as high as one third (Scherer, 2002). It has been suggested that this might result from a lack of integrating the end users with CCN in the development process of the product (Prior, 2010a).

Taking this hypothesis as a starting point, the objective of this master project was to involve people with CCN in the development of an AT device from the very

beginning and to an extent that it was the users who decided what the software product would be.

2 Background

This chapter describes the setting in which the software development project has been undertaken. It provides the reader with an introduction to CCN, highlights the importance of communication and explains the term AAC. It further discusses the abandonment rate of AAC devices, presents participatory design as a possible development approach and outlines the project aims of this thesis.

2.1 Complex Communication Needs (CCN)

CCN describe the more severe end of the communication impairment severity spectrum. Difficulties that people with CCN face are speech which is difficult to understand, problems in understanding what is said to them, and/or problems in expressing themselves due to limited vocabulary and skills to create sentences (Iacono, 2004).

A person may have complex communication needs for multiple reasons which can be classified as developmental or acquired disabilities. In the first case, the person is born with the disability or it develops within the few years of their life; consequently it may affect their social or cognitive development (Department of Communities - Disability Services, 2009, Iacono, 2004). Examples of developmental disabilities are Down syndrome, cerebral palsy and autism. Acquired disabilities resulting from an illness or injury that are associated with communication impairments are, for example, traumatic brain injuries, spinal cord injuries and strokes, but also degenerative diseases such as multiple sclerosis or motor neurone diseases (Department of Communities - Disability Services, 2009, Iacono, 2004). In any case, people with CCN generally have a combination of motor, language, cognitive and sensory impairments which is why they typically

rely on multiple modes to meet their communication needs (Blackstone and Berg, 2003)

2.2 Importance of Communication

“Information sharing” is the intended purpose of the device to be developed within the scope of this Master project. The term is included in the meaning of the word “communication” as can be seen when considering its Latin origin: “communicare”. “Communicare” has two meanings: “to inform/to communicate” and “to share/to do something together” (Martin, 2004). This highlights that beyond the pure exchange of information, communication also includes sharing of experiences and emotions. Thus, communication can be considered fundamental to all aspects of life as well as for quality of life. Successful communication makes it possible for people to express their wants and needs, but also their thoughts and personality. It allows them to build relationships, make decisions and take part in social activities (Department of Communities - Disability Services, 2009). Consequently, communication can be considered as essence of life (Waller, 2009) and has been declared a human right by The United Nations‟ “Universal Declaration of Human Rights” (1997).

2.3 Augmentative and Alternative Communication (AAC)

AAC is a means for non-speaking people and people with speech impairments to communicate. As the name suggests, it includes methods that enhance (augment) communication, such as facial expressions or gestures, and those that replace conventional forms of communication (alternatives), e.g. using a symbol board to

communicate. An example for the importance of AAC can be seen from the following quote by a man with severe cerebral palsy:

> *"If you want to know what it is like to be unable to speak, there is a way. Go to a party and don't talk. Play mute. Use your hands if you wish but don't use paper and pencil. Paper and pencil are not always handy for a mute person. Here is what you will find: people talking; talking behind, beside, around, over, under and through, and even for you. But never with you. You are ignored until finally you feel like a piece of furniture." - Rick Creech (Musselwhite and St. Louis, 1988)*

There are different types of AAC which can be sub-divided in unaided and aided systems.

Table 1: Types and sub-divisions of AAC (adapted from Iacono, 2004).

Types of AAC	
Unaided	
• Informal	*Examples:* Facial expressions Body language Gestures Vocalisations Idiosyncratic movements
• Formal	Sign language
Aided	
• Low-tech	*Examples:* Communication boards/books with words, symbols or pictures
• High-tech	Single message switches (e.g. Big Mack) Text-to-speech communication aides (e.g. LightWriter) Voice output devices with static or dynamic displays

As can be seen from Table 1, unaided AAC does not involve any equipment. Informal methods can be in particular useful for AAC users to express their feelings. However, in order for them to be interpreted correctly the communication

partner must be familiar with the behaviour patterns of the AAC user which might be affected by physical disabilities. In contrast, aided AAC uses devices to convey messages. Depending on whether the devices are electronic or not, these systems are referred to as low-tech or high-tech AAC devices. The latter range from simple single message switches to highly sophisticated computer-based voice output devices with dynamic and multi-level displays.

2.4 Abandonment of AT

Abandonment of AT describes the discontinued use of a device by the user although professionals consider the system appropriate. On average, the percentage of devices that are left behind is one third (Scherer, 2002) which corroborates findings of an earlier study by Phillips and Zhao (1993). However, it should be noted that the exact percentage depends on the degree to which the device is required, i.e. the more a person depends on a type of device, the lower its abandonment rate (Phillips and Zhao, 1993). For AAC systems, Johnson et al. (2006) found an abandonment rate of 28.68%. Their study identified a number of factors leading to abandonment such as little support from family, therapists and assistive technology specialists; lack of motivation, i.e. the user preferring other, simpler means of communication; stigmatization; lack of ongoing adjustments and resulting poor fit of the system as well as poor usability and limited functionality. Moreover, missing user involvement in the design process of the product has been cited as a major contributor to the high rate of abandonment by Riemer-Reiss and Wacker (2000) as well as Scherer (2002).

2.5 Including People with Communication Impairments in the Design of Software Products

There is an increasing awareness of the need to include users at all levels of the software development process in general (Sanders, 2002) and also specifically in the development and design of AT (Williams et al., 2008). However, there is debate to what extend users with CCN can be involved in the development process. Whilst Seelman et al. (1998, p. 24) advocate involvement of individuals with disabilities "in setting the research agenda, developing research questions, participating in the research as researchers, advisors, and consultants, testing research ideas, and most importantly, evaluating the results of the research", Newell and Gregor (2000) stress that this might be possible in sociological research, but not in User-Centred Design (UCD). For them, users can be involved, but the activities mentioned above require a trained researcher. Using an UCD approach with people who use AAC is very difficult and is therefore often neglected. However, Waller et al. (2005) overcame this problem by training people with CCN, families and AAC professionals in UCD workshops. In their understanding, including all affected parties in the design process from the beginning is vital for the development of usable products. Successful examples for this approach are the development of the Portland Communication Aid prototype (Allen, 2005) and the CHAMPION project (Prior, 2010a). Designer-facilitated Participatory Design (PD) methods, such as physical models rather than sketches for requirement gathering, were used to integrate AAC users into the development process from the very beginning.

2.6 Project Aims

The aim of this project was to develop a software system for and with adults with severe disabilities that would allow them to share information while using Prior"s guidelines: “Working with adults with complex communication needs in human centred design” (2010b). It involved working with end users in all stages of the software development process and included identifying the project remit.

3 Human-Centred Design (HCD) Methodology and Models

HCD is one of the fundamental concepts of Human Computer Interaction (HCI). As described in the standard ISO 9241-210:2010 (International Organisation for Standardization), it is an approach to interactive systems development with the goal of making systems usable and useful, i.e. increasing their effectiveness, efficiency and user satisfaction. To achieve this, HCD focuses on the user, in particular on user needs and requirements, but also human factors/ergonomics and usability knowledge. As a result, the user is involved in every stage of the development process, evaluates alternative designs and has consequently direct influence on the development of the software.

According to Sanders and Stappers (2008), we are moving from the design of products and technology to designing for people‟s purposes which centre around people‟s needs or societal needs such as unmet needs of people with medical conditions.

The ISO standard 9241-210:2010 lists a number of reasons for the use of HCD. In the context of this project, the most relevant reasons are the increased accessibility for disabled people, the ease of use of the product with resulting reduction of training and support costs and the improved user experience. On the operational side, the HCD approach also aids the definition of functional requirements, reduces the risk of not meeting the stakeholders‟ requirements and the product being rejected by users.

Moreover, the standard emphasises that the human-centred approach is to be understood as complementing existing system development approaches. The

process model of the Wheel (Helms et al., 2006) is an example for this and will be elaborated in the next section of this chapter.

3.1 Discussion of Different User-Centred Lifecycle Models

The lifecycle **Model of the Wheel** developed by Helms et al. in 2006 represents a combination of four earlier models which are in chronological order Royce‟s Waterfall model (1970), Boehm‟s Spiral Model (1988), Harton and Hix‟s Star life cycle (1989) and Cognetics‟ Logical User-Centre Interaction Design (LUCID) framework which was originally developed in 1998. Before presenting the Model of the Wheel itself, some brief explanations of the four models which were of influence are given.

In contrast to the classical, strictly linear **Waterfall model** (Royce, 1970) where each stage of the development process must be completed in its entirety before the next stage can begin, Boehm‟s **Spiral life cycle** model (Boehm, 1988) takes an iterative, incremental and risk driven approach.

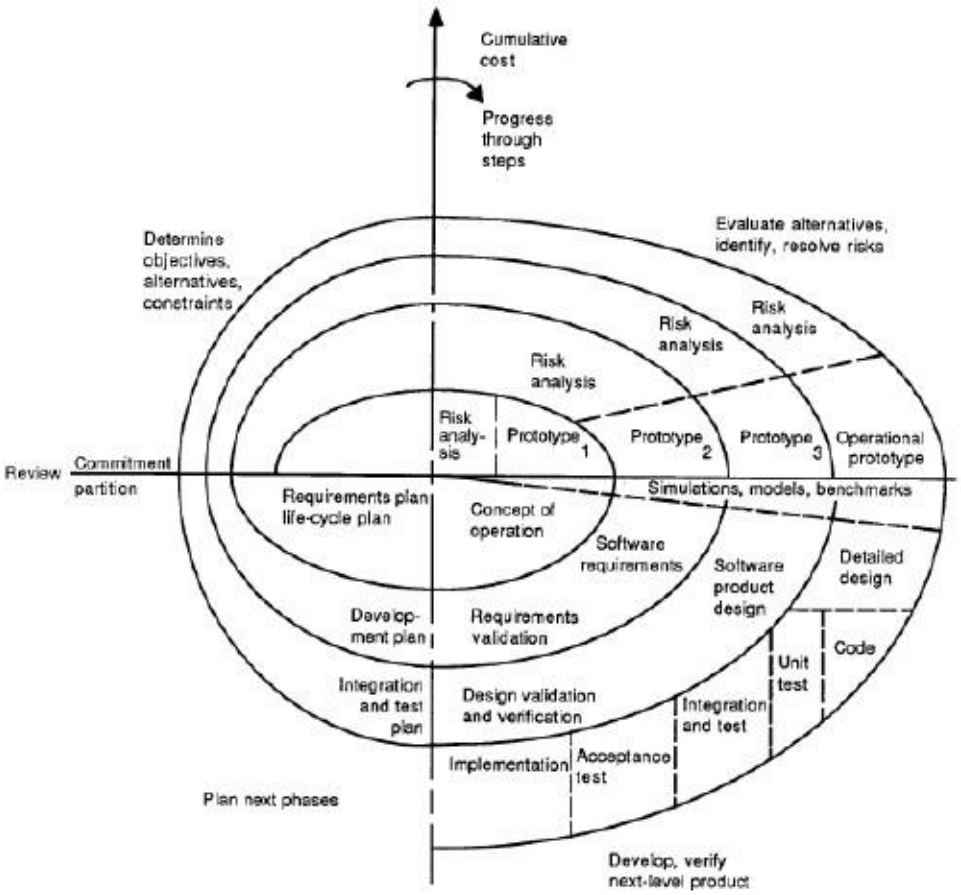

Figure 1: Boehm's Spiral life cycle model (adapted from Boehm, 1988).

As can be seen from Figure 1, each cycle begins with the identification of the objectives of the current cycle while considering alternatives and imposed constraints such as costs or schedule. At the next stage (quadrant), risks are analysed and evaluated with the help of prototypes. The biggest risk is then dealt with first and can therefore be considered the determining factor of the development in each cycle. In a next step, results are reviewed and the next iteration is planned. Advantages of this approach are that design flaws are discovered early as software is produced early in the life cycle (Boehm, 1988). Furthermore, the high amount of risk analysis is especially beneficial for mission-

critical projects. However, it should be noted that risk analysis requires high levels of expertise which may not always be given.

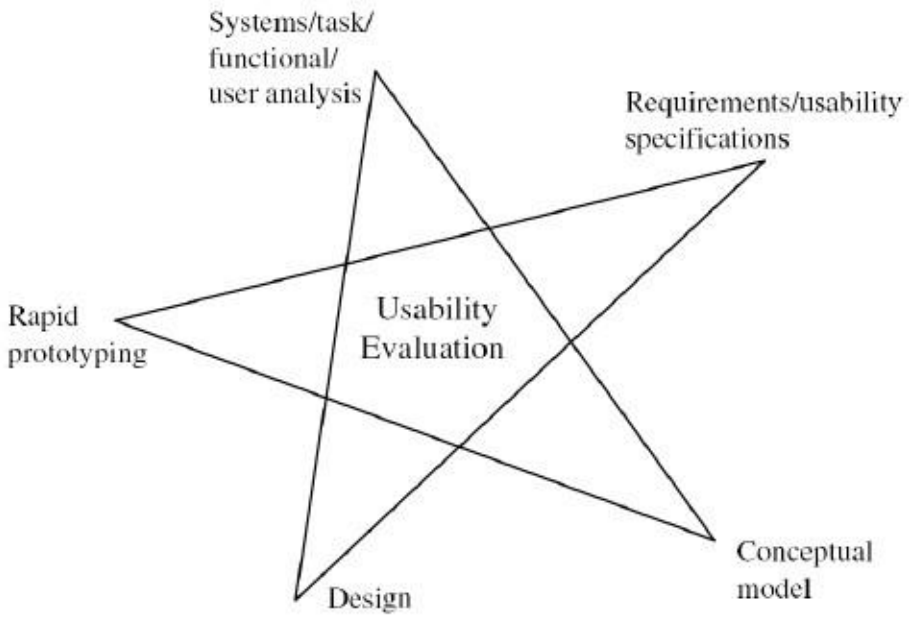

Figure 2: The Star life cycle concept (adapted from Hartson and Hix, 1989).

The **Star life cycle** concept is a usability engineering process that was developed by Hartson and Hix in 1989. As can be seen from Figure 2, usability evaluation is the central point of the model. It interconnects the different and distinct, but otherwise unconnected, development activities at the points of the star. As these are in no particular order, there is no predefined sequence of activities which the developer has to follow in the development. After an activity is completed, it is evaluated before the next activity is started. The goal of this approach is a continual evaluation and iteration during the development process with smaller loops of iteration than the spiral model. A disadvantage of this concept might be the missing notion of progress towards the final product.

The **LUCID framework‟s** goal is to offer product users the “five E‟s”: effectiveness, efficiency, engagement, error tolerance and ease of learning (Kreitzberg, 2008). The framework consists of a series of six stages which are: envision, discovery, design foundation, design detail and build release. Each stage itself entails the elements depicted in Figure 3, where the component “Activities” is replaced with the core activity of the current stage.

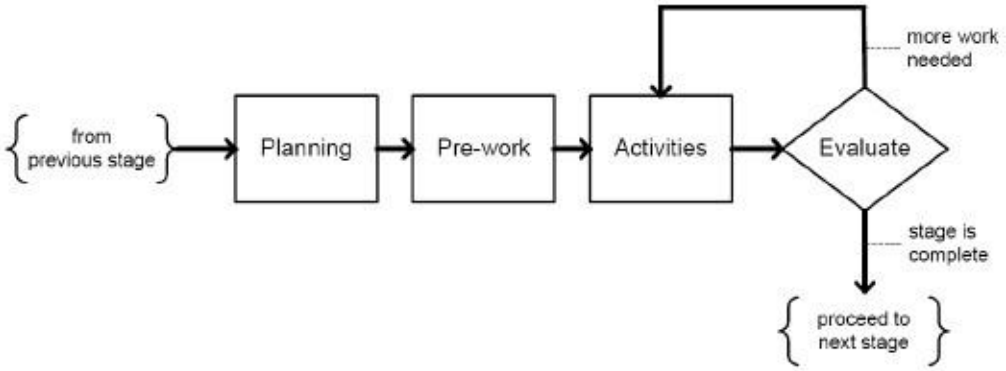

Figure 3: LUCID stage flow (adapted from Kreitzberg, 2008).

From this latter framework, Helms et al. (2006) extracted the four basic activity types for interaction design, i.e. analysis, design, implementation and evaluation. They constitute the four quadrants of the wheel‟s mini-spirals which can be seen in Figure 4 and which themselves have been adopted from Boehm‟s Spiral model. The global usability evaluation hub is borrowed from Hartson and Hix‟s Star lifecycle and the direction of evolution is inherited from the classical Waterfall model.

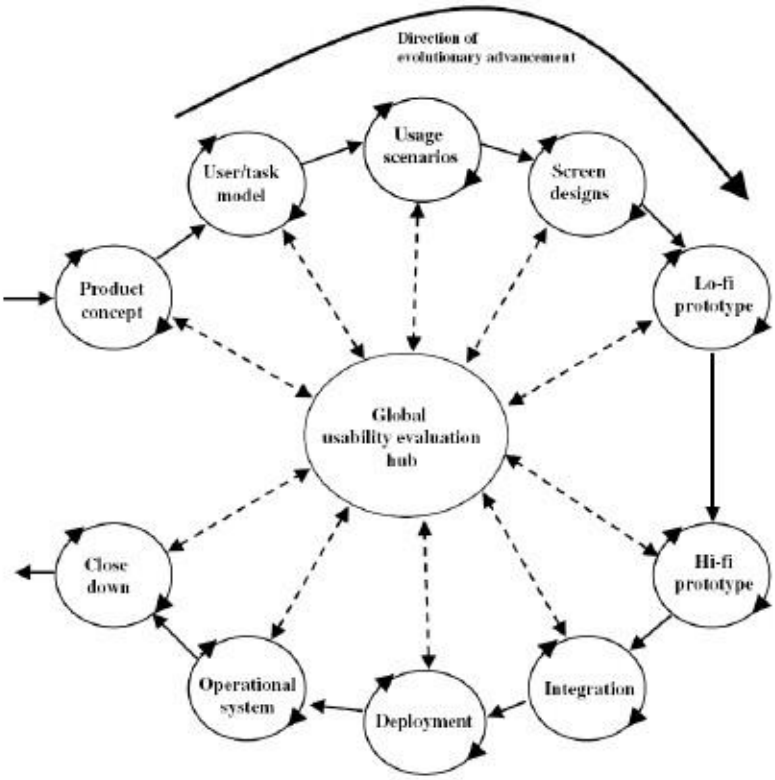

Figure 4: The Wheel process model (adapted from Helms et al., 2006).

The process **Model of the Wheel** can be customised to the needs of a specific project as well as it can be adjusted halfway-through if required due to changes in budget, schedule or resources. In order to produce an instance of the wheel the appropriate cycles are selected and techniques for the activities in each cycle are specified. The evaluation hub can be considered a higher-level controlling activity determining the next most appropriate cycle (Helms et al., 2006).

The model adheres to the four key principals of usability engineering (Hewett and Meadow, 1986) which are:

- Early - and continual - focus on users (specific techniques are explained in section 3.2)
- Integrated design (starting the project at various places at once while

recognising that usability is important)

- Early - and continual - user testing (using mock-ups, simulations, early prototypes or demonstrations)
- Iterative design (identification of requirement changes, ability and willingness to make changes)

To conclude, the process Model of the Wheel seems worthwhile pursuing as it manages to combine major software development processes with usability engineering and interaction design activities while putting the user at the centre of all activities.

3.2 Techniques Needed to Engage in User-Centred Design

When working with users, different techniques are available at different stages of the design process to elicit user needs and attitudes, to generate ideas, but also to receive feedback from users through testing and evaluating prototypes. A number of key methods are described in this section to give insight in how users can be involved in software design and development.

Focus groups are group discussions which are often used in the analysis phase of a development project. They aim at revealing user attitudes and expectations towards a certain product or concept (Wilhelm, 2010). The participants can be either users or experts. Usually two-hour meetings are arranged with at least six participants to discuss new concepts and to identify product issues. The sessions are led by a moderator who keeps the group‟s focus and ensures that all participants get a chance to express their opinion. The strengths of focus groups are their informal character, the fact that the participants are in a peer-to-peer

situation and the spontaneously generated ideas. On the other hand, several focus groups are required to get a representative result and participants may have difficulties understanding and formulating their needs (Nielsen, 1997, Wilhelm, 2010).

Another qualitative research method is the **semi-structured interview.** In preparation for the interview the aim of the interview should be determined and a representative sample selected. A characteristic of the semi-structured interview is that the sequence of questions is determined by an interview-guide whereas the questions are open-ended to make the interview flexible (Hove and Anda, 2005). Following the flow of conversation, new extending or echoing questions can be added as sort of probes. The benefits of this method are its flexibility, interactivity and that high qualitative data can be generated. On the downside, it is expensive to do and time consuming. Furthermore, there is the risk of interviewer effects and response bias.

In early user-centred design approaches users were passive subjects. The **co-design** approach in contrast, considers end-users the experts because of their experience. In this emerging discipline formerly referred to as participatory design, designers and people not trained in design collectively work together. As Sanders and Stappers (2008) point out, the expert role of the user is important for learning about the user as well as the context of use, for idea generation and the development of concepts. The task of the researcher/designer is to support the experts by providing them with appropriate tools that allow them to express their ideas, for example, through paper prototypes. On a critical note, this approach assumes that all people are creative which is obviously a broad generalisation.

A method that can be used as soon as a first prototype is developed is user **observation.** This is a very unobtrusive way to learn about the interaction between the end-user and the product. If the user has given consent, the interaction can also be video recorded for later analysis. Attention should be paid to extraneous factors such as environment, interruptions and distractions. However, a clear limitation is that the observer can see what is happening but without knowing why. In addition, intentions, feelings and satisfaction cannot be measured (Holzinger, 2005).

A **cognitive walkthrough** is a task-specific usability inspection method which is usually performed by a group of designers and developers. The activity aims at identifying usability issues that the targeted end-user group may encounter by going through each step of specific tasks. The focus is on exploratory learning as well as on how easily future users can complete each task. The method can be applied early in the design/development process (before coding commences) and is, therefore, an inexpensive way to gain usability insight. However, it should be noted that it is based on assumptions of the designers/developers and that there is a risk of paying too much attention to details at the beginning of a project (Holzinger, 2005).

Heuristic evaluation is the most common informal usability inspection method and can take a holistic view of a running system. Nonetheless, it can also be applied earlier in the development process, e.g. in the specification stage. Following a recognised list of usability principles (e.g. Nilsen‟s Usability Heuristics (Nielsen, 2010c)), usability or domain experts steps through the interface of the application and judge each interactive element. The evaluations are carried out individually by each evaluator to ensure independence and eliminate potential

bias. Nielsen and Molich (1990) recommend that heuristic evaluations should never rely on a single evaluator as an aggregation of independently captured opinions from a number of different people will most likely always yield more usability issues. Nielson and Molich showed that the ideal number of evaluators in terms of the cost-benefit ratio is 3 – 5 people. The strengths of heuristic evaluations are that they are quick to perform, relatively inexpensive, intuitive to do and that they can be conducted early in the development process. However, specialised products require expert evaluators who may be difficult to find. Another disadvantage is that problems may be identified, but usually no suggestions for possible solutions are elicited.

However, using the techniques summarised above with severely disabled people is problematic. Traditionally, people who use AAC have only been used in final evaluations or at most as informants (Olsson, 2004). Therapists have instead been used in the design of systems. As mentioned earlier, in order to involve adults with severe disabilities in the project, guidelines developed by Prior (2010b) were followed.

3.3 Guidelines

Prior‟s rationale for the guidelines “Working with adults with complex communication needs in human centred design” (2010b) was the increasing number of computer users with cognitive and developmental disabilities and the high abandonment rate of AT. Prior infers that it may be possible to reduce the abandonment rate through the inclusion of end users in the design process. The guidelines (Prior, 2010b) are based on the standard ISO-13407 (Human-centred design processes for interactive systems) and provide guidance on how design

processes can be conducted when involving users with CCN. The guidelines, summarised in Table 2, are intended for developers or researchers who will be working with users with CCN.

Table 2: Prior's guidelines – Working with adults with complex communication needs in human centred design (adapted from Prior, 2010b).

Summary of Prior's Guidelines
Preparation phase
• Before starting any work with people with CCN, carefully examine the ethical situation, special procedures are most likely required when working with disabled people. • As recruiting a representative sample of disabilities and needs is rather difficult, purposive or judgemental sampling may be necessary to cover most impairments. Charities who work with people with CCN may be able to initiate contact to potential participants. • If incentives are to be given to participants, make sure these do not interfere with benefit rules. However, often participants are happy to volunteer. • Short notice cancellations due to illness are more likely to occur and should therefore be accounted for in the project plan. • Before starting the actual sessions it is suggested to meet the participants and their support workers to make the participant feel comfortable. • After going through the participant information sheet, informed consent can be obtained by asking yes/no questions to confirm that potential participants understand and agree to the study. In particular questions to make sure they want to participate and know how they will contribute to the study may not be missed.
During the sessions
• At the beginning of each user session the previous session should be reviewed to help the participants recall the steps undertaken so far. • During the sessions, attention should be paid that the work is not too tiring and extra time for breaks should be factored in. • The style of speech should be neither too complicated or technical nor condescending, but participants should feel as equals with the designers. • In order to overcome hesitations of the participants when giving requirements to researchers, group discussions might be a solution. • Allow plenty of time for participants to answer questions. • Provide participants with storyboards or videos on current problems to help them • imagine possible solutions. Also encourage users to imagine how other potential users would interact with the system. • Create tangible prototypes with participants rather than sketches as these are impossible to draw with reduced dexterity. • Explicitly encourage participants to give negative feedback explaining them that

finding flaws in the technology during the development will improve the quality of the finished product.
- The intrusiveness of video recording for the purpose of gathering feedback can be minimised if planned carefully.
- Evaluations are not limited to observations as participants may be trained to perform heuristic evaluations. Also encourage support workers to take part in the evaluations.
- Designers should try to include as many accessibility modes and adaptations as possible with the possibility of switching them on and off.
- Provide participants with a session summary and feedback at the end of each session.

After the session

- Encourage participants to “promote” the participation in the research study/design project among other potential end-users.
- In order to avoid a feeling of abandonment for the participant at the end of a study, possibilities of participation in other projects should be discussed.
- At the end of the study, personal feedback on the project and their contribution should be given to participants rather than a thank-you letter.

4 Requirement Gathering

This chapter begins with a description of the initial and particular steps required due to working with disabled people before the actual start of the software development project. This led to the development of the actual project plan which can be found in

Appendix **1.** After an initial idea finding process with the participants, market research was conducted and prototypes developed in order to specify the requirements.

4.1 Getting the Project Started

As the project‟s participants would be disabled people, the author was required to apply for a **Scotland Disclosure.** This certificate issued by Disclosure Scotland, an Executive Agency of the Scottish Government, is designed to enhance public safety. It ensures that vulnerable groups in society, e.g. disabled people, are protected by checking that people wanting to work with them do not have a criminal history.

In addition, **ethical approval** needed to be sought from the School of Computing as the project would involve participants. The author informed the Ethics Committee that the project would be considered part of Suzanne Prior‟s PhD thesis and was given positive response to pursue the project.

The **recruitment of participants** was facilitated by a speech and language therapist from the NHS (National Health Service). Having worked with the School of Computing before, she gave the author the opportunity to pitch the project idea to her clients with CCN in one of their fortnightly meetings allowing the author

purposive sampling of her participants. As it could not be assumed that the potential participants of the project were literate, the author created an A3 poster outlining the project idea in Boardmaker symbols (see Appendix 2). After a successful presentation as such, the author found it difficult to say whether the potential participants liked the idea of the project or not. Although all the support workers were very much in favour of the project, the potential participants‟ facial expressions and body language did not give much away for the author.

Several weeks passed and further explaining to parents and other support workers, who were not present during the presentation, was necessary (see project summary in Appendix 3). In the end, seven participants were successfully recruited (see Table 3). Participant B joined the group of participants at the end of the project to perform a heuristic evaluation of the final prototype.

Table 3: Participant profiles.

Parti-cipant	Age	Gender	Condition	Mode of Communication
A	24	female	Cerebral palsy	Dynavox AAC device, paper QWERTY keyboard, pointing at white board with a couple of options, severe dysarthric speech
B	30	female	Cerebral palsy	Lightwriter text-to-speech device, nodding and shaking head, severe dysarthric speech
C	46	female	Cerebral palsy	Palm-top communication aid with Bliss symbols broken --> nodding and shaking head, severe dysarthric speech
D	50	female	Cerebral palsy	Eye gaze
E	24	male	Traumatic injury due to car accident	Dynavox AAC device, thumb up and down
F	40	male	Cerebral palsy	Word map, nodding and shaking head, gestures, severe dysarthric speech
G	52	male	Cerebral palsy	Head switch scanning device, eye gaze
H	71	male	Cerebral palsy	Dysarthric speech

4.2 Idea Finding Process and Getting to Know the User Group

The author used the first user session with each of the seven participants to introduce herself and to get to know the users – in particular, what they liked to do, how they communicated, if there was something on the communication side of things that frustrated them and if they could think of anything they wished existed. As an ice-breaker, the author showed the participants a PPT-slideshow with a few pictures of herself at different places in Scotland. The pictures were chosen with the intention that they should spark conversation, which they did.

With the initial questions leading to the topic of “information sharing software”, the author learned and experienced that all of the participants had their ways of expressing their wants and needs whether by indicating answers to yes/no-questions with their head, their eyes or by thump up and down. Utterances were made, word mats utilised, high-tech AAC-devices used (operated either by hand or by head switch) as well as a paper QWERTY-keyboard.

All participants had in common that they liked to socialise - some in the traditional form of a night in a pub while others preferred Facebook (a social networking website). Another observation made by the author made that the participants seemed to enjoy it when their support workers or parents reminded them of past experiences. This became apparent to the author when seeing the participants moving idiosyncratically, i.e. rocking vigorously when excited.

Table 4: Different types of conversation (adapted from Waller, 1992).

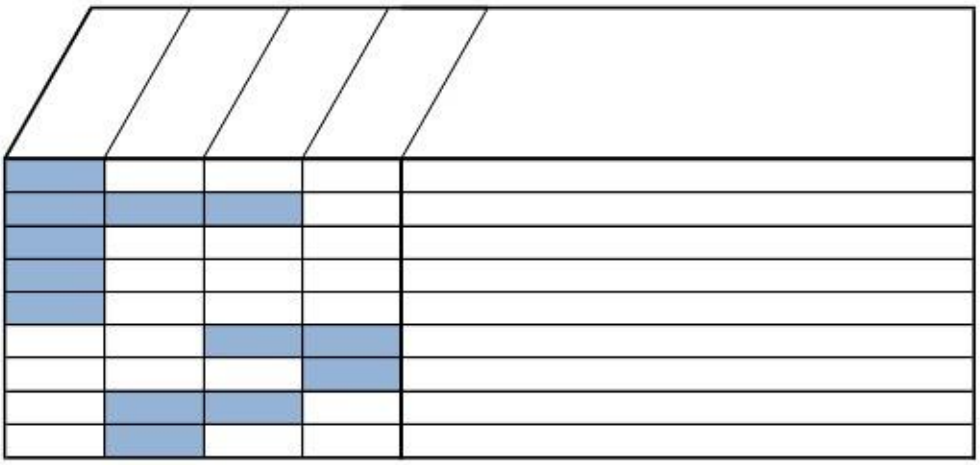

Table 4 shows the four types of conversation according to Waller (1992) and gives examples for each classification. The participants and the author agreed that the first two types, i.e. formulaic conversation and basic need/wants, are managed to a satisfactory degree by all participants with their existing modes of communication. Summing up, the author and the participants came to the conclusion that there was room for improvement regarding “reusable conversation” telling personal stories. Literature confirms that telling stories is important in life as it gives meaning to life and helps to create one‟s self-concept (Polkinghorne, 1995, Waller, 2009). This in mind, the idea of developing a talking photo album was born. The four main findings leading to the idea were:

- All participants enjoyed looking at the author‟s photos during their first session.
- One of the participants turned out to be a keen photographer (having a camera that can be mounted onto her wheelchair).
- All participants liked to share past experiences.
- One participant wished to have a text-to-speech generator/screen-reader as her literacy was very limited.

4.3 Market Research

This section describes the market research undertaken to investigate what kind of talking photo albums for people with CCN already exist. An evaluation of a commercially existing photo album follows and lays open several design flaws of a talking photo album advertised as communication aid.

4.3.1 Commercially Available Talking Photo Albums

An extensive internet research has shown that there is a considerable number of talking photos albums on the market, the vast majority highly resembling each other and identical in their functioning (Quality Enabling Devices Ltd, 2010, Augmentative Communication Inc., 2010, Needapresent.com, 2010, Talking Products Ltd, 2010, TERS ELECTRONIC LTD, 2010). Pictures are held in individual transparent pockets with a squeezable button to activate a recorded message. To record a message, the record button and the activation button need to be pressed simultaneously while the user has to speak into the photo album‟s build-in microphone to record a message.

Only one digital photo album was found (Photos-Speak Company, 2010). In this album an audio file is attached to each picture.

A different approach to a talking photo album is the so called V Pen (Voice Pen). It comes with a voice symbol software that makes it possible to print sound onto paper by adding a nearly invisible bar code on the print which can then read by the V-Pen (Ability World Ltd, 2010).

It is interesting to note that talking photo albums are sold in the context of communication aids for people with communication impairments (Augmentative Communication Inc., 2010, Inclusive Technology Ltd, 2010, Quality Enabling Devices Ltd, 2010, Ability World Ltd, 2010) as well as in that of photo gifts in general (Needapresent.com, 2010, Talking Products Ltd, 2010, TERS ELECTRONIC LTD, 2010). In both application areas the concept of talking photo albums seems highly appealing to users as 5-star customer reviews (Amazon.com, 2010) and feedback from participants of this study demonstrate.

4.3.2 User Testing and Evaluation of a Commercially Available Talking Photo Album

Apart from the recently launched V Pen which follows a different approach, it is surprising that there are no adjustments made to the photo albums to make them more user-friendly for their target user group when advertised as a communication aid. In order to evaluate its usability for people with CCN, one of the highly resembling talking photo albums was bought (see Figure 5).

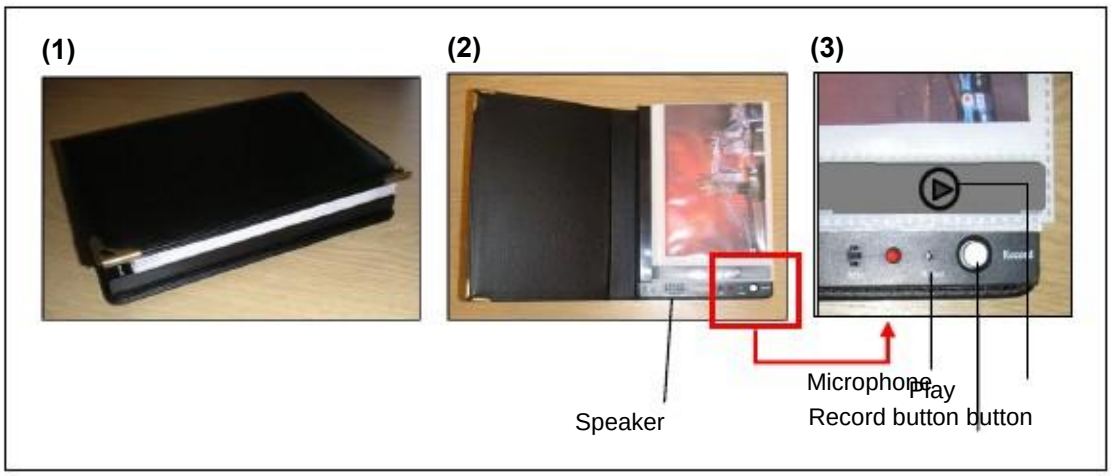

Figure 5: Commercially available photo album.

In individual sessions, the user groups, each consisting of a person with CCN and their support worker, were asked to test the setup of the photo album and the actual use by the AAC user. Subsequently, the groups were given the task to perform a heuristic evaluation in order to find usability problems in the design. The evaluators (user group 1 – 4) scrutinized the photo album with regard to (1) physical appearance, (2) appropriateness for users with CCN, (3) fulfilment of purpose, (4) ease of use, and identified a number of problems (see Table 5).

Table 5: Usability problems identified in heuristic evaluation.

p1 User group	p2 User group	p3 User group	p4 User group	**Usability Problems**
				Not very robust
				Recordings can be easily deleted by accident
				Nearly impossible to handle with reduced dexterity
				Many steps required to create an album
				No interactive conversation
				Setup requires speech
				Cannot be created independently by AAC user
				Buttons are very small
				Recording time too short

Each of the blue cells in Table 5 indicates the finding of a usability problem by one of the user groups. The table shows that on the one hand, there is an overlap between the usability problems identified by the different user groups. On the other hand, some problems have only been found by one or two user groups. This demonstrates that it is worthwhile having several independent evaluators which Nielsen (2010b) confirms in his analysis of the number of evaluators required for

an evaluation. For this reason, the author has limited the number of evaluators to four.

The evaluated talking photo album was perceived as ***not very robust*** by one of the evaluators, a characteristic considered important if the book was targeted at people with CCN as spastic movements might destroy the album involuntarily.

Recordings can be easily deleted by accident – the reason for this problem lies in the fact that when the play button on a photo page is pressed during the recording process, buttons on pages underneath the current page might be pressed as well and so other photo descriptions might potentially be overwritten. To overcome this potential risk, the photo page that is meant to be described needs to be lifted up to ensure that only one play button is pressed at a time. This, however, is very unlikely to be feasible for people with CCN.

The fact that the album is ***nearly impossible to handle with reduced dexterity*** refers partly to the previously described problem but also to the complicated procedure of recording a message which involves two small buttons being pressed simultaneously as described in section 4.3.1.

One user group pointed out that ***many steps are required to create an album.*** The picture needs to be taken, it needs to be developed, potentially picked up in a store, it needs to be inserted into the photo album and finally a message needs to be recorded. It was pointed out that nearly all of these steps constitute actions which would need to be carried out for and not by the person with CCN.

Furthermore, it was observed that the commercially available photo album provided ***no interactive conversation*** as such as everything about the picture would be said in one go - missing out the concept of turn-taking completely.

Setup requires speech – at a first glace this problem seemed almost ironic. A communication aid for people who cannot speak that requires speech input. However, many communication aids require a setup by an able-bodied person.

It was concluded that the examined photo album **cannot be created independently by AAC users.** The reason for this lies predominantly in the fact that speech input is required for the setup, but also in the fiddly play button that needs to be pressed in order to activate the speech.

This latter point – ***buttons are very small*** – was explicitly identified by two of the four user groups. Everyone agreed that this was an issue that should be addressed when designing a device for people with reduced dexterity.

Finally, it was noted that the ***recording time is too short.*** Ten seconds do not allow describing the story of a picture in much detail.

4.4 Prototyping and Evaluation

Following the first user sessions and the definitions of the theme, several prototypes were created and evaluated.

4.4.1 Co-design Sessions

In preparation of the co-design sessions, participants were provided with a range of photos from which they were asked to choose two. They then had to imagine

they had taken the photos themselves and were showing them to a friend telling him/her all about it. The photo descriptions were analyzed as to what questions had been answered by the descriptions of the photos. The results were the following questions: where, when, what, who, feelings.

Figure 6: Users with CCN during individual co-design session.

The next round of meetings represented the major **co-design sessions** during which each participant created a user interface prototype of The Talking Photo Album application. Paper squares with question symbols (the five questions identified in the previous session), foam buttons in different colours and shapes as well as a range of photos and a white board were provided. Building physical

prototypes rather than sketches, as it is common procedure with able-bodied people, proved to be a viable solution. The participants enjoyed this active work (see Figure 6). Depending on the degree of the participant‟s disability the buttons were placed onto the board through the participants‟ own hands, through support workers after the participants with CCN had chosen one of many options given to them or in one case through eye gaze and with help of a transparent tray. The results from these individual sessions can be seen in Figure 7.

Figure 7: Results from co-design session of photo album screen with users with CCN

Prototypes number (1) and (2) show a clear spatial separation of the question buttons, the three facial expression feeling buttons and the Yes/No buttons. This

differentiated arrangement of buttons corresponds to the cognitive capabilities of the participants experienced by the author during the duration of the study. Prototype (3) has a neat arrangement of buttons, but there is no distinction made between the different categories of buttons. The last three prototypes do not seem to follow any concept. The conclusion drawn from this exercise by the author was that spatial separation of buttons mattered more to the participants than attributing each button category a particular colour.

To test whether the participants would understand the concept of an interactive photo album using a touch-screen, the author conducted a **Wizard of Oz experiment.** A photo description was prepared for the session assistant (the "wizard") who was to simulate the voice of the photo album application. A third person was invited to have a conversation with the participant with CCN about the picture. The participant with CCN pressed the appropriate foam buttons on the interface prototype of the photo album, thus triggering the „voice" of the photo album and holding a successful conversation about the photo.

4.4.2 Usability Button Game

A general concern was the choice of the right button size. This was an important decision as the users with CCN and reduced dexterity should not become frustrated due to poor usability when using the photo album application. For this reason the author developed the Usability Button Game (see Figure 8) with three button sizes.

As the imaginary touch-screen in the Wizard of Oz Experiment was successfully used by the participants, the author chose to use the Panasonic Toughbook H1

Health (see Figure 9) available within the research group because of its touch-screen functionality and its robustness.

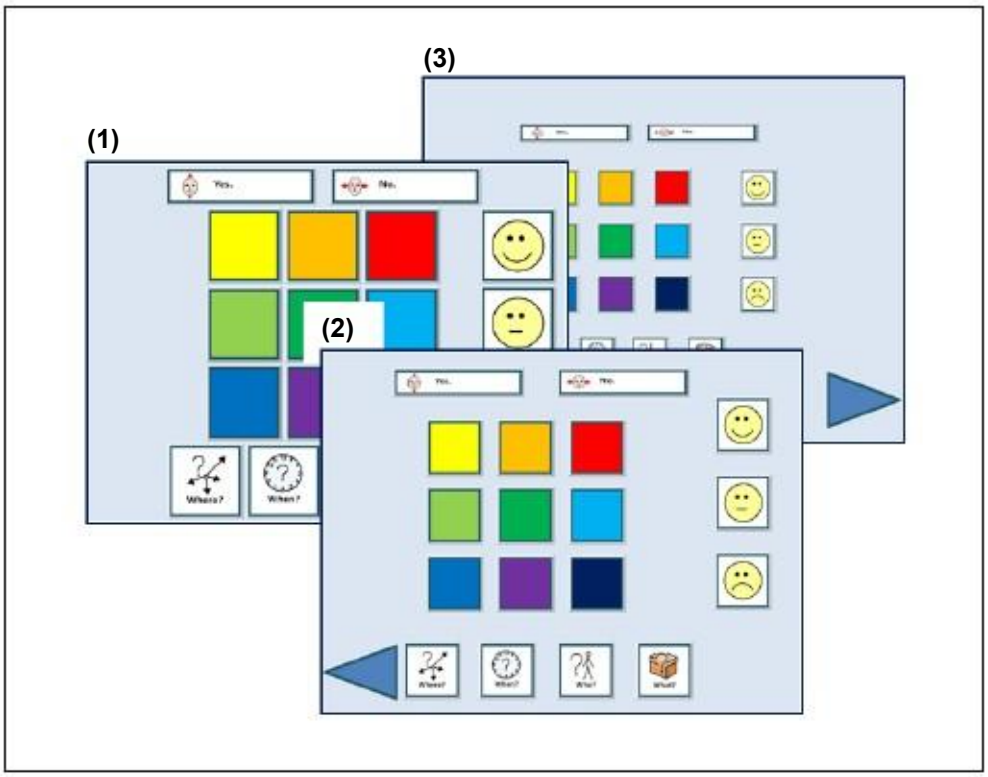

Figure 8: Usability Button Game (with 3 button sizes).

In the Usability Button Game, the nine coloured squares in the middle of the screen ask a question when pressed which the user with CCN had to answer by touching the corresponding button around the outer edge just like in the photo album application to be developed. All three screens (Figure 8 (1-3)) were tried out with regard to ease of use. The participants with CCN unanimously preferred the medium button size. Prior concern from colleagues of the author that the participants with CCN might feel ridiculed when asked to play this game and evaluate the button size did not occur, quite the contrary happened. The

participants enjoyed to hear the voice saying “That‟s correct!” each time they pressed the right button and did not mind the voice saying “Sorry, please try again.” when they had chosen an incorrect button.

However, some participants had problems using the touch-screen without a keyguard which they were used to from other AT devices. A keyguard is a clear plastic board with holes corresponding to buttons on the touch-screen onto which it is placed. It supports the user‟s hand and prevents that they press buttons by mistake.

4.4.3 Keyguard

In order to make the application accessible to a wider audience, the author created a keyguard out of Perspex with the help of a laser cutter. The first keyguard prototype can be seen in Figure 9 (1 + 2). It is propped up with toothpicks to avoid the Perspex touching the screen which would lead to permanent triggering of the touch-screen mechanism. The second keyguard prototype (Figure 9 (3)) is slightly larger than the screen of the Toughbook and is, therefore, resting on the slightly higher brim of the screen. Furthermore, edges were re-adjusted to the shapes on the screen and made round to make them smoother to touch.

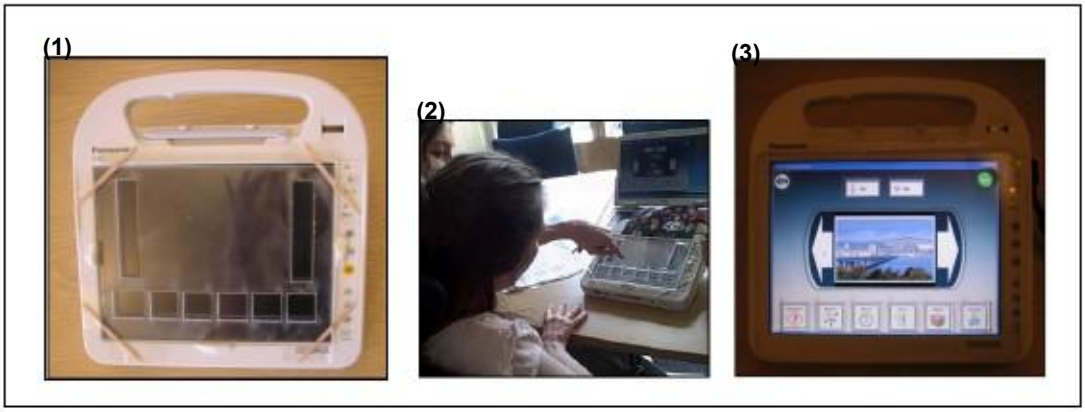

Figure 9: Keyguard prototype #1 (1 + 2) and #2 (3) for the Toughbook.

4.4.4 PowerPoint (PPT) Prototypes

An interactive Microsoft Office PowerPoint slideshow with a text-to-speech generator was chosen as next prototype medium as it was considered relatively simple to develop, but very effective in its use.

Figure 10 (2) shows the text description entry screen, (3) shows the feeling radio buttons and (4) shows the actual photo album screen with Yes/No buttons and an exit button at the top of the screen, the photo in the middle with Previous/Next buttons on either side, the feeling button at the right side and the remaining Where/When/Who/What buttons below the photo. Participants were able to press the buttons on the photo album screen which played back the descriptions which were entered beforehand.

Figure 10: PPT-prototype #1.

While the participants tried out and tested this first PPT prototype, suggestions for improvement were made by all parties involved. The Previous/Next buttons proved to be too narrow and as such not easy to use by the participant with CCN due to their reduced dexterity. The participants with CCN pointed out that they would not require Yes/No buttons as they were able to communicate agreement or disagreement without the help of buttons. The author and support workers noticed that the communication via this prototype tended to be rather one-sided. The participants with CCN always only replied to questions they were asked by their conversation partner.

The above mentioned suggestions for improvement were taken into consideration in the second PPT prototype (see Figure 11). Improved features were the enlargement of Previous/Next buttons, the removal of Yes/No buttons and the addition of a Question button. This Question button, when pressed, turns the audio buttons for the next button push into question mode and allows users with CCN to ask their conversation partner a question. The event is announced when the Question button is pressed with “I‟ve got a question for you.”.

Figure 11: PPT-prototype #2 – photo album screen.

When in question mode the Where button uses the location description of the current photo and asks when pressed “Have you been to <location of current photo>?”. The When button picks up the date of the current picture: “What did you do in <date of current photo>?. The following three buttons have standard questions when in question mode, i.e. “Who was with you?”, “What did you do there?” and “How did you like it?”.

The evaluation process was guided by a questionnaire for both PPT-prototypes and the usability button game (see Appendix 4). While the appearance of the PPT-prototype #2 was rated positively by the participants, it became obvious that a more advanced facility was required to administer multiple pictures. Furthermore, the Yes/No buttons were reconsidered and finally re-introduced as they were thought to be useful in situations where the user with CCN is showing The Talking Photo Album to someone not familiar with their way of saying yes and no.

4.5 Requirement Specifications

Leading on from the market research, co-design, prototyping and evaluation activities, requirements for The Talking Photo Album application were specified.

There are two different kinds of requirements in software engineering: functional and non-functional. While the former describes tasks a system must perform, the latter consists of constraints upon a system and/or the developer/designer (Wiegers, 2003). Usability is a non-functional requirement (Lauesen and Younessi, 1998). As usability requirements were of particular interest in this project, they are listed separately.

Gathering requirements from the end-users in this project was challenging due to the communication limitations. Therefore, family and support workers were equally consulted.

Table 6: Functional requirements for The Talking Photo Album.

Functional Requirements
FR1: Login procedure Description: The Talking Photo Album shall require a user to login using a username and password. Rationale: Prevents unauthorised access to photos of others, e.g. in care homes.
FR2: Choice of options Description: After the user is logged-in, the system shall provide the user with a choice of uploading a photo, describing a photo and viewing the photos in the album and listening to their description. Rationale: Direct access enables users to directly jump to the task they want to carry out without running through a particular sequence of steps.
FR3: Photo upload (user perspective) Description: The system shall provide the user with a possibility of uploading a picture available anywhere on their device/computer (hard drive, USB-stick, CD) into The Talking Photo Album. Rationale: Users need to be able to insert photos into the system. Different upload sources provide flexibility.
FR4: Photo upload (system perspective) Description: The system shall make a copy of the photo that is to be inserted into the system in a folder that is created with the name “The Talking Photo Album” in “My Documents”. Rationale: Saving a copy in a specially created folder for the photo album ensures that the photo is still available when the data carrier is removed from the device/computer or the location where the photo was stored is changed.
FR5: Photo album description setup Description: The system shall allow the user to save descriptions for each photo for the following questions: where?, when?, who?, feeling? Rationale: These questions were found to be the ones generally asked when looking at photos.
FR6: Auditory feedback (in description setup section) Description: All symbol buttons in description setup section shall give auditory feedback. Rationale: This makes the photo album accessible to a wider range of users with CNN who might be not familiar with the symbol system used.

FR7: Photo loop functionality in the description setup Description: The system shall allow the user to go forward and backward through the photos in an endless loop to choose for which photo they want to edit the description. Rationale: Creating a loop allows the user to get to photos at the end of the photo album quicker by going backwards than moving through the whole album to get to the end.
FR8: Photo loop functionality in the album Description: The system shall allow the user to look at the photos going forwards and backwards in an endless loop. Rationale: Creating a loop allows the user to get to photos at the end of the photo album quicker by going backwards than moving through the whole album to get to the end.
FR9: Introduction phrase Description: The system shall allow users to initiate a conversation about the photos they want to show by saying so. Rationale: Users with CCN should have the ability to initiate a conversation about their photos.
FR10: Transition phrase Description: The system shall allow users to move a conversation to the next/another photo they want to show by saying so. Rationale: Users with CCN should be in control to say when they want to move to the next/another photo.
FR11: Playback of descriptions when corresponding button is pressed Description: The system shall speak the description entered in the description setup section when the corresponding symbol button is pressed. Rationale: Allows users to say specific details or answer particular questions.
FR12: Use of symbols to convey information Description: The system shall not require literacy and use symbols in addition to written labels. Rationale: A high percentage of people with CCN has no or only limited literacy skills and often uses symbol systems instead.
FR13: Photo album with questions buttons Description: The system shall have individual buttons for the questions: where?, when?, who?, what?, feeling? Rationale: These split-up descriptions foster turn-taking in the conversation which is considered desirable as it is common in conversations between people without speech impairments.

FR14: Possibility for the user with CCN to ask questions Description: The system shall allow its users to indicate that they have a question and to ask questions regarding one of the five photo description divisions: where?, when?, who?, what?, feeling? Rationale: This feature makes the “photo conversation” resemble a conversation between people who don‟t have a speech impairment.
FR15: Go-back functionality Description: The system shall allow the user to return to the action choice overview page. Rationale: This feature allows the user to navigate back and forth through the application.
FR16: Logout functionality Description: The system shall have an exit/logout possibility to “close” the photo album on each interface screen. Rationale: The user should be able to exit the photo album at any time.
FR17: No speech input required for setup Description: The system shall not require speech input to setup the descriptions for the photos. Rationale: If users are literate, they should be able to setup the photo album on their own and without help from a third person.
FR18: Offline availability Description: The Talking Photo Album shall be available offline. Rationale: Does not limit access to users with an internet connection.
FR19: Operational on different Windows operating systems Description: The Talking Photo Album shall be fully functional on Windows XP, Windows Vista and Windows 7. Rationale: These are the most common Windows operating systems in use, so makes the program accessible to the majority of users.

Table 7: Non-functional requirements for The Talking Photo Album.

Non-functional Requirements (1)
NFR1: Time frame of project Description: The project shall be presented on 1st September 2010. Rationale: Specification of the MSc Project – Submission Guidelines.

NFR2: Purpose of the software to be developed Description: The finished software application shall give people with CCN the opportunity to share information. Rationale: Specification of the Master thesis subject/title.
NFR3: Choice of database Description: The database shall be build using Microsoft Office Access. Rationale: Microsoft Office is a widely-used application suite and includes MS Office Access which is a pseudo-relational database management system which does not require internet access This is of importance as internet access is often restricted in care homes where a proportion of potential end-user live.
NFR4: RAM requirement for photo album application Description: The system should not require an excessive amount of RAM. Rationale: The photo album application should be usable on a wide variety of devices.

Table 8: Usability requirements for The Talking Photo Album.

Non-functional Requirements (2) Usability
UR1: Comprehensibility of error messages Description: Error messages generated should be clear, informative and concise. Rationale: Gives information to the user as to how the error message occurred and how to avoid similar errors in the future.
UR2: Robustness of the system with regard to input Description: The system shall be robust regardless of input where possible. Rationale: Prevents errors occurring due to incorrect user input. This is necessary as some characters have a special meaning in the languages used in development.
UR3: Confirmation messages Description: Users should be informed that a task has been completed successfully through a confirmation message. Rationale: Displaying a confirmation message of the task being completed increases the satisfaction and confidence of the users in the system.

UR4: Installation of The Talking Photo Album on robust device
Description: The Talking Photo Album shall be installable on a robust device that is not easy to destroy involuntarily.
Rationale: The device needs to be suitable for users with CCN who have reduced motor control and reduced dexterity.

UR5: Physical size and weight of devices for the photo album
Description: The Talking Photo Album shall be installable on portable devices and thus do not have excessive sizes and weights.
Rationale: The photo album should be easy to take along/to transport.

UR6: Appropriateness for users with CCN
Description: Users with CCN shall be able to operate the finished photo album on their own.
Rationale: The application is meant to foster (independent) communication of users with CCN.

UR7: Size of buttons on the actual photo album
Description: Users with CCN shall be able to comfortably select a target button on the actual photo album.
Rationale: The photo album application should be physically easy to use by users with CNN.

UR8: No limit on description length
Description: Users shall be able to enter descriptions as long as they wish without any restriction in length.
Rationale: The user should not feel restricted in any way when describing the photo.

UR9: No extensive training for the actual photo album
Description: Users with CCN shall be able to use the actual photo album without any extensive training.
Rationale: The steps to carry out for using the photo album should be easy to learn for users with CCN.

UR10: Colour and design of The Talking Photo Album
Description: The colour of the photo album shall have a plain and minimalistic design.
Rationale: Users shall not be distracted and/or irritated by the colour or design of the photo album.

UR11: Memorability of how to use the album
Description: The user shall be able to remember the necessary steps to use to photo album after a period of not using the system.
Rationale: The Talking Photo Album is an application which is most likely not used on a daily basis. Therefore, users should be able to easily re-establish proficiency as otherwise the application might be abandoned.

UR12: User-comfort while using the photo album
Description: The user shall be relaxed and confident when using the photo album application.
Rationale: It should be pleasant for users to use The Talking Photo Album and not require too much effort as otherwise they may not want to use the system.

During the time-span of the project, the requirements continually evolved and reassessments were made. The requirements listed above represent those that were taken into consideration in the creation of the final prototype. Some requirement had to be abandoned due to time constraints. In particular, these were the photo delete function, and the username and password creation.

5 Software Design and Implementation

5.1 Use Cases

Use cases are an informal way to describe requirements in a narrative format.

More precisely:

> *"A use case is a description of the possible sequences of interactions* [and variants thereof] *between the system under discussion and its external actors, related to a particular goal." (Cockburn, 2000, p.15)*

For the photo album application, three actors were identified: the support worker (see Figure 12); the illiterate user with CCN (see Figure 16); the user with CCN and literacy skills (see Figure 17); and. In the following, use case diagrams for each actor, descriptions of the use cases with their basic and alternative flow and supplementing interface sketches are presented.

Support Worker

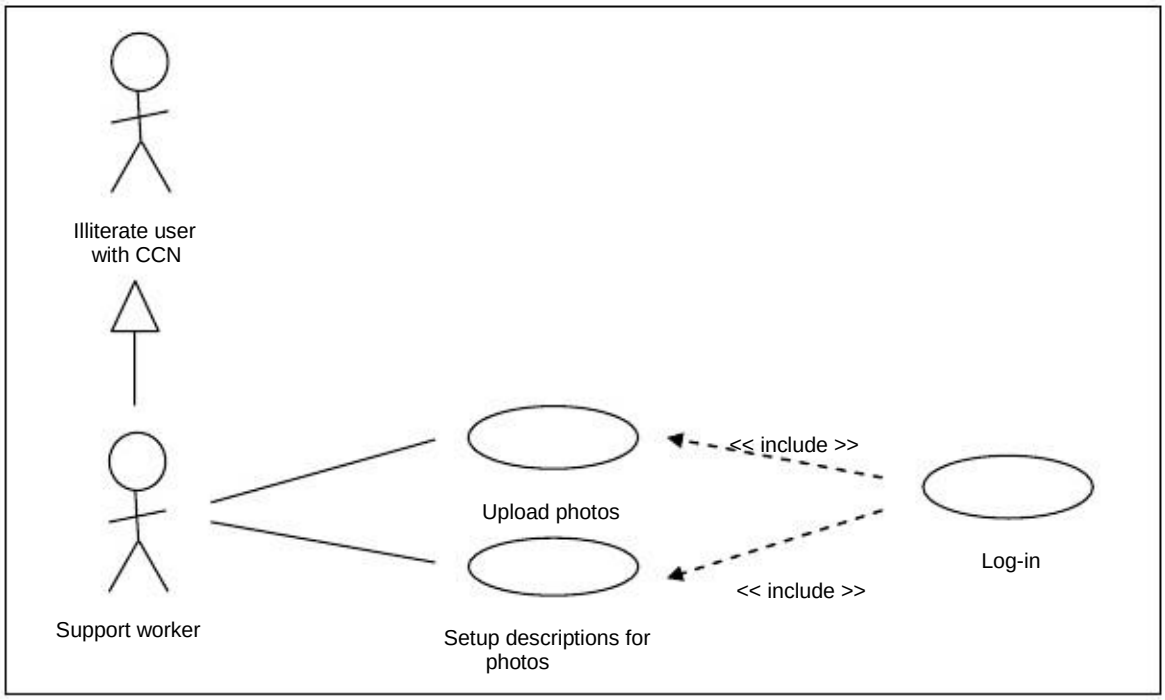

Figure 12: Use case diagram for support worker.

Table 9: Use case 1 for support worker.

Use Case 1
Basic flow:
UC1-BF: Login The use case begins when the support worker/user with CCN opens The Talking Photo Album application. System: Requests the support worker to enter their username and password. Support Worker: Enters their user name and password using a keyboard. **(A1)** System: Verifies the login credentials and provides options for uploading photos, describing photos and opening the actual photo album on a new screen (see Figure 13).

Alternative flow:	
UC1-AF1: Incorrect username and password Support worker/user with CCN has entered an incorrect username and password.	
System:	Displays error message “Sorry, you username or password is invalid!”, thus informing the support worker why the login failed. Return to basic flow of events where support worker enters username and password.

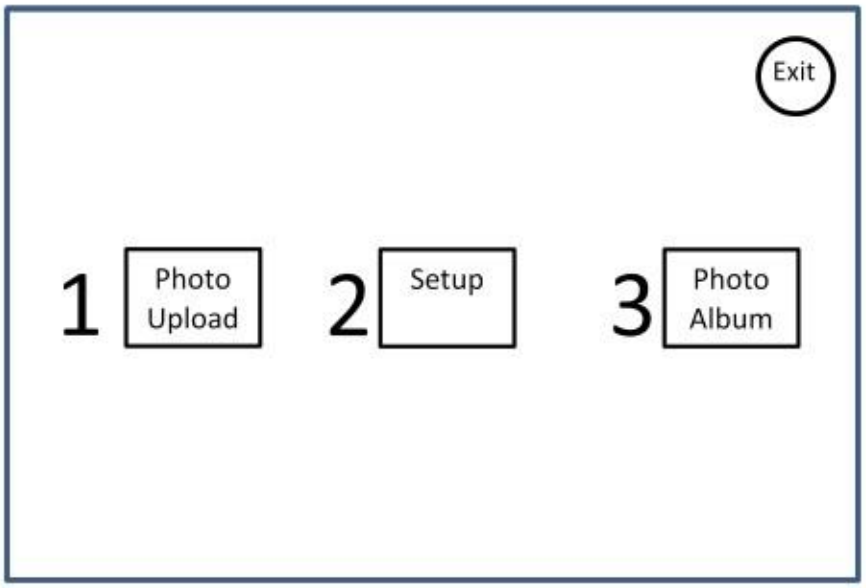

Figure 13: Interface sketch of option screen.

Table 10: Use case 2 for support worker.

Use Case 2	
Possible basic flow:	
UC2-BF: Upload of photos The use case begins when the support worker opens The Talking Photo Album application.	
System:	Perform The „Login“ use case
Support Worker:	Selects the option to upload photos.
System:	Displays new screen with two numbered buttons: 1 - Browse for photo, 2 - Photo upload (see Figure 14).
Support Worker:	Selects button “1 - Browse for photo”. **(A1)**

System:	Opens a file open dialogue box.
Support Worker:	Selects photo file for upload into The Talking Photo Album. Presses button “2 – Photo upload”.
System:	Displays message “Upload successful!” **(A2)**

Possible alternative flows:

***1 – Support worker exits**
The support worker has the option to exit the photo album application at any time.

Support worker:	Selects the exit-button.
System:	System returns to login page.

***2 – Support worker returns to the welcome/home page**
The support worker has the option to return to the welcome/home page at any time.

Support worker:	Selects the back-button.
System:	System returns to welcome/home page.

UC2-AF1: Wrong order of buttons
Support worker has pressed button “2 – Photo upload” prior to searching and selecting a photo with button “1 – Browsing for photo”.

System:	Displays error message “Please first search and select a photo using button 1”. Return to basic flow of events where support worker selects button “1 – Browse for photo”.

UC2-AF2: Upload of existing photo
Support worker has selected a photo for upload that already exists in The Talking Photo Album.

System:	Displays error message “Photo already exists in photo album!”. Return to basic flow of events where support worker selects button “1 – Browse for photo”.

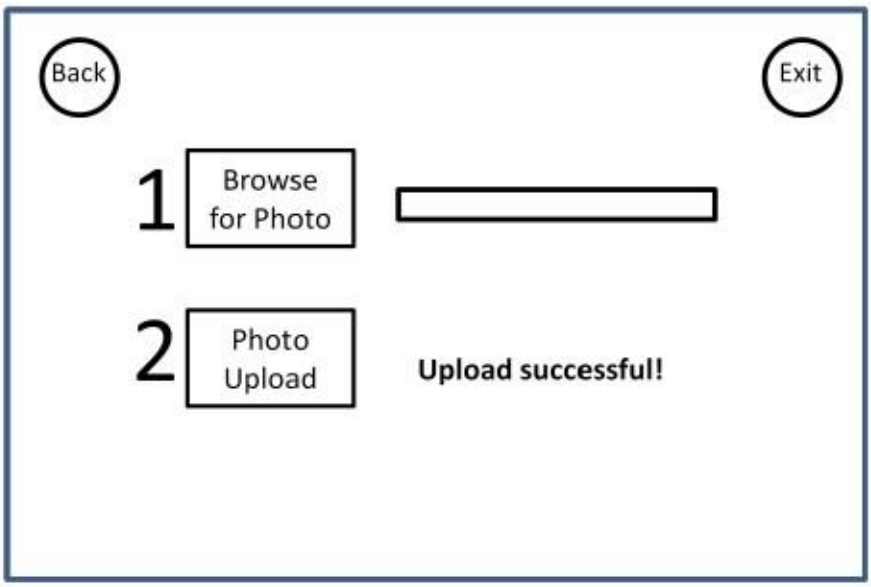

Figure 14: Interface sketch of upload screen.

Table 11: Use case 3 for support worker.

Use Case 3	
Possible basic flow:	
UC3-BF: Setup of photos The use case begins when the support worker opens The Talking Photo Album application.	
System:	Perform The „Login" use case
Support Worker:	Selects the option "Setup".
System:	Displays new screen (see Figure 15).
Support Worker:	Describes the photo by completing the answer to the question written underneath photo (in the text box) and selecting the save-button. **(A1, A2)**
System:	Commits the entry to the database and displays the next of the five questions for each picture.
Possible alternative flows:	
***1 – Support worker exits** The support worker has the option to exit the photo album application at any time.	
Support worker:	Selects the exit-button.
System:	System returns to login page.

UC3-AF1: Different picture
The Support worker wants to describe a different photo than currently displayed.

Support worker:	Moves to the desired photo using the previous- and next-button on either side of the photo.
System:	Interface moves to desired photo. Return to basic flow of events where support worker describes the photo by completing the answer to the question written underneath photo (in the text box) and selecting the save-button.

UC3-AF2: Change of description
The Support worker wants to change a description of a photo that already exists.

Support worker:	Moves to the desired photo using the previous- and next-button on either side of the photo.
System:	Interface moves to desired photo and allows the support worker to overwrite the existing description. Return to basic flow where the support worker selects the save button.

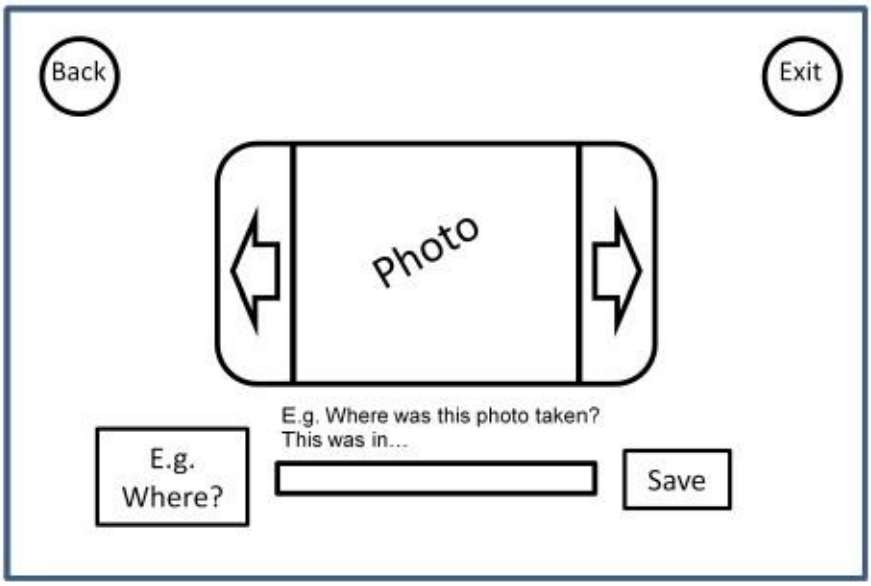

Figure 15: Interface sketch of setup screen.

Illiterate User with CCN

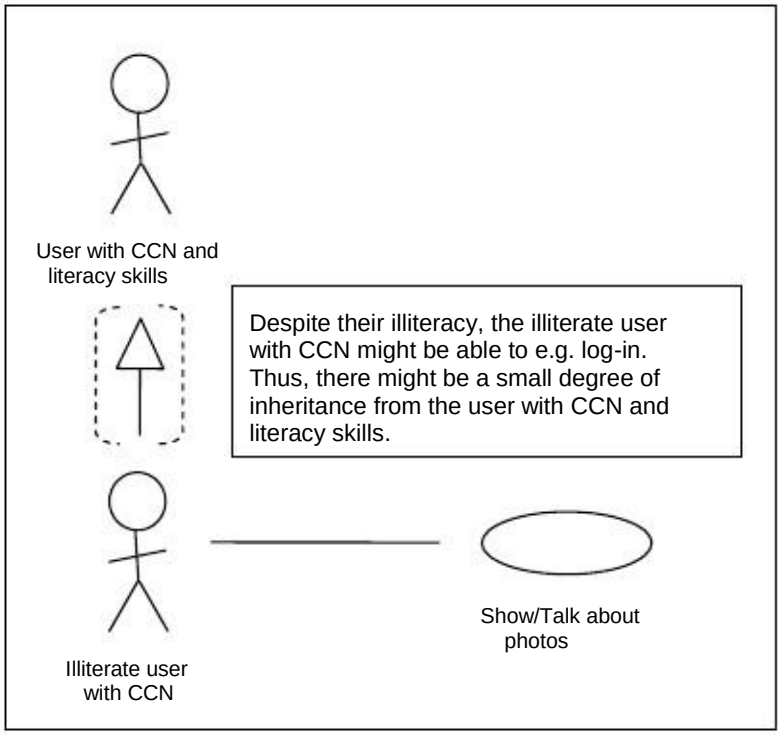

Figure 16: Use case diagram for illiterate user with CCN.

Table 12: Use case for illiterate user with CCN.

Use Case 1	
Possible basic flow:	
UC1-BF: Operating the photo album, i.e. showing and talking about photos in the album The use case begins after photos have been uploaded and described in The Talking Photo Album and the illiterate user with CCN is given the device with the actual photo album screen (see Figure 17).	
Illit. user with CCN:	Starts the conversation by clicking on the photo.
System:	"Would you like to see some pictures?"
Conversation partner:	"Yes, let‟s look at some photos."
Illit. user with CCN:	Presses where-button.
System:	"This in the Cornwall."
Conversation partner:	"It looks pretty, did you go there on holiday?"
Illit. user with CCN	Presses the yes-button.
System:	"Yes."
Illit. user with CCN	Presses what-button.
System:	"I was visiting family."

Conversation partner:	"Who went with you?"
Illit. user with CCN:	Presses who-button.
System:	"I went there with my parents."
Conversation partner:	"Was it this summer?"
Illit. user with CCN:	Presses no-button.
System:	"No."
Illit. user with CCN:	Presses when-button.
System:	"This was in the summer of 2008."
Conversation partner:	"Seems to have been a lovely summer day?"
Illit. user with CCN	Presses the yes-button.
System:	"Yes."
Illit. user with CCN:	Presses feeling-button.
System:	"I really liked the warm weather."

Possible alternative flows:

***1 - Next photo with agreement from conversation partner**
The illit. user with CCN has the option to ask their conversation partner if he/she wants to see the next picture at any time.

Illit. user with CCN:Presses the picture.
System:"Would you like to see another picture?"
Conversation partner: "Yes!"
Illit. user with CCNPresses the next-button.
System:Displays the next picture.

***2 - Next photo without prior announcement**
The illit. user with CCN has the option to move to the next photo at any time.

Illit. user with CCN	Presses the next-button.
System:	Displays the next picture.

***3 – Illit. User with CCN wants to ask a question**
The illit. user with CCN has the option to ask their conversation partner a question at any time.

Illit. user with CCN	Presses the question-button.
System:	"I"ve got a question for you."
Illit. user with CCN	Presses the where-button.
System:	System goes into question mode and adds the location of the current picture into the standard partial question "Have you been to…?". The partial questions are button specific as are the words that are filled in.
	"Have you been to: Cornwall?"
Conversation partner:	"No, but I would really love to!"

***4 – Illit. User with CCN wants to exit the photo album**
The illit. user with CCN has the option to exit the photo album at any time.

Illit. user with CCN	Presses the exit-button.
System:	System returns to login page.

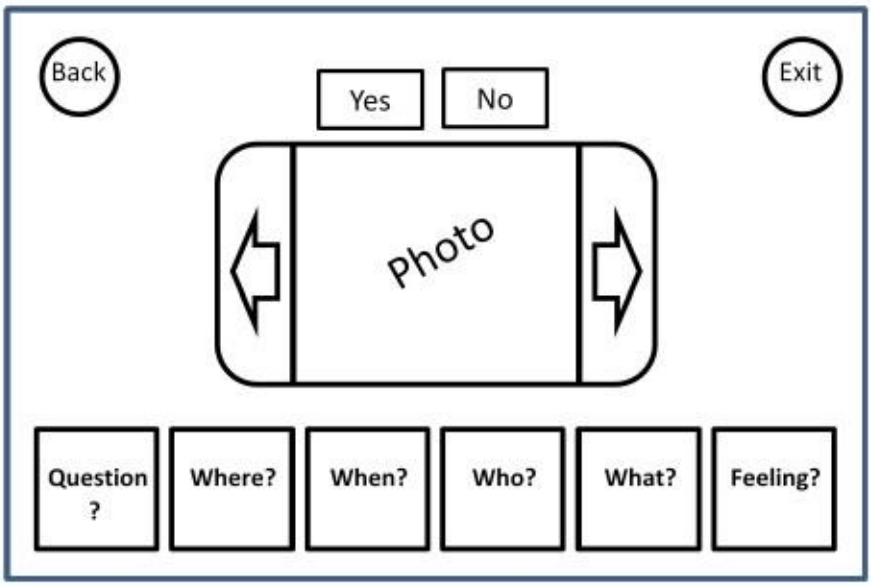

Figure 17: Interface sketch of photo album screen.

User with CCN and Literacy Skills

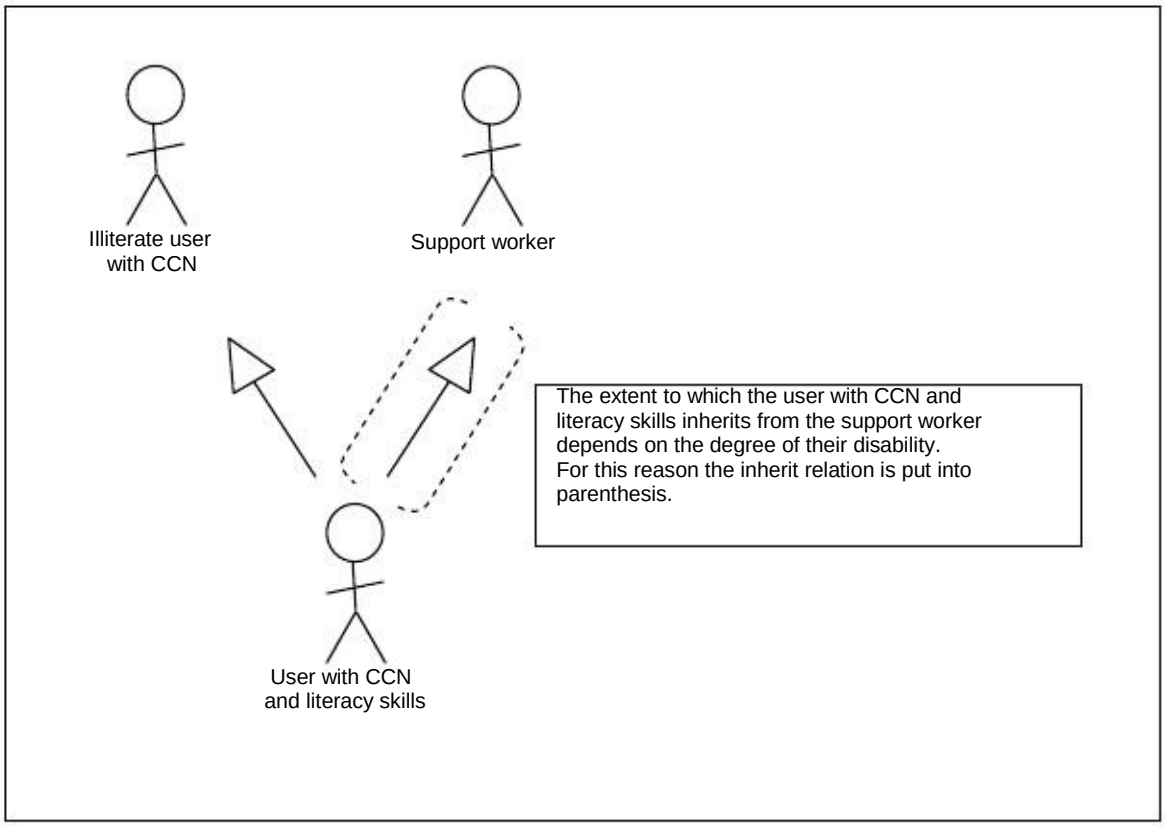

Figure 18: Use case diagram for user with CCN and literacy skills.

Depending on the degree of their disability, literate users with CCN will be able to perform the „Login" (use case) themselves and potentially the photo upload (use case) as the cognitive load should be manageable for them. As full literacy in people with CCN is scarce (Dahlgren Sandberg et al., 2010), users with CCN will be likely to require help/support for describing the photos (setup use case). This is in particular the case as the descriptions need to be grammatically correct sentences in order to be understood by conversation partners later on. As a result, there is no clear allocation of use cases for users with CCN and literacy skills, because the level of independence depends on the degree of disability of the individual. Generally speaking, a user with CCN and literacy skills will, therefore,

be able to perform all use cases an illiterate user with CCN can perform and additionally some use cases that support workers will perform for illiterate users with CCN.

The development of these use cases allowed putting the functional requirements into a real context. Furthermore, their analysis highlighted alternative flows some of which had still to be incorporated into the design; these were in particular error messages helping the user to understand why an error occurred.

5.2 Overview of Program Architecture

Based on the prototypes, requirements and the use cases, a screen structure was defined (see Figure 19)

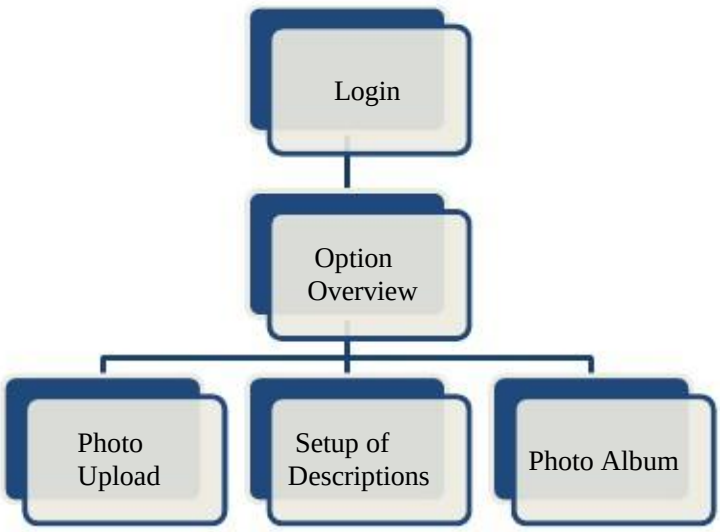

Figure 19: Screen structure of The Talking Photo Album application.

5.3 Entity-Relationship (ER) Diagram

When working with the early PPT-prototypes, it became clear that a system was required to upload and manage multiple images. It was decided that a database would be ideal to hold the required information the pictures as well as the standard fragments that would be used by the system.

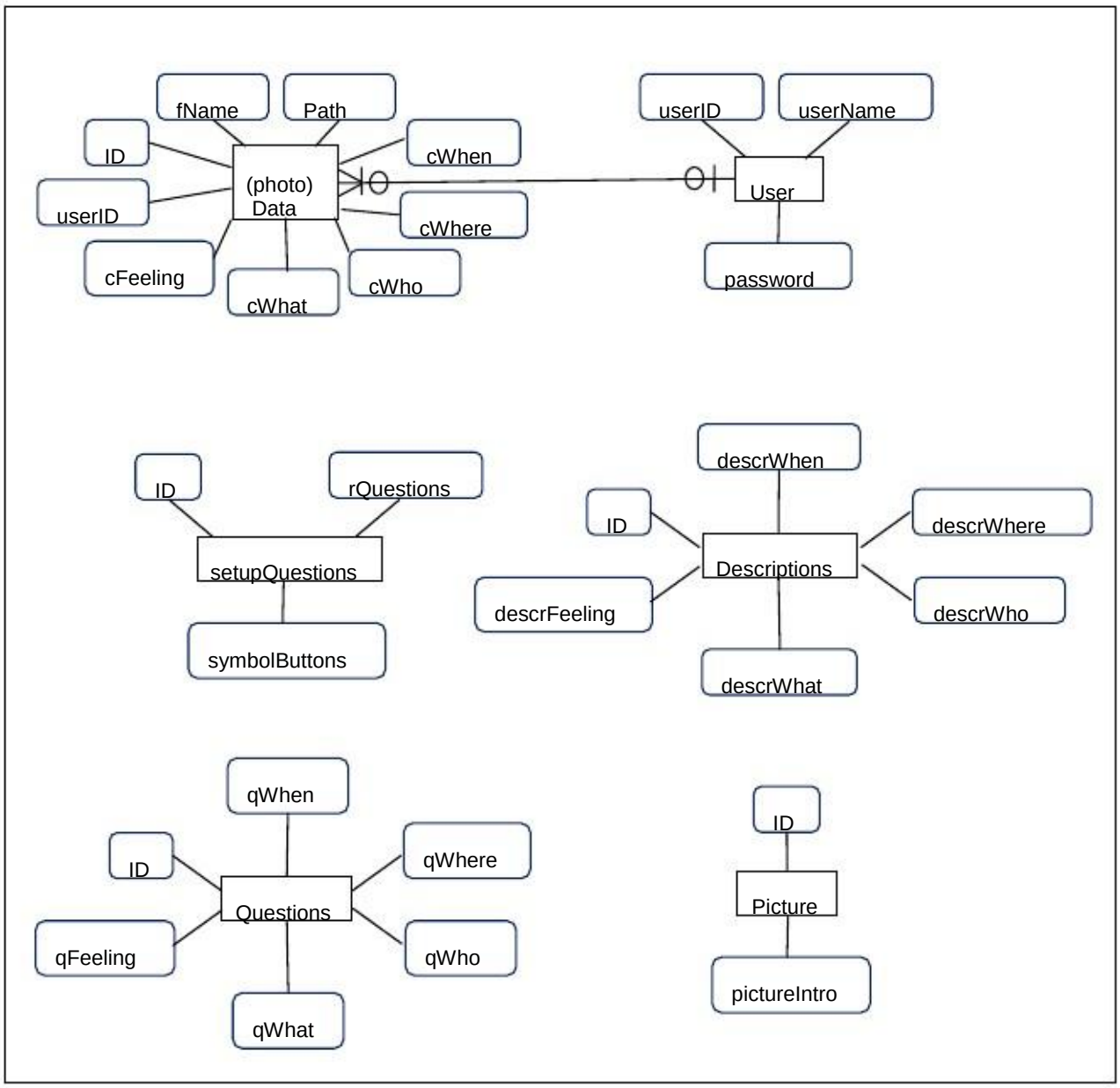

Figure 20: ER-Diagram of The Talking Photo Album database.

The **(photo) Data table** contains all information that make up the descriptions of the photos which can be accessed through the Where/When/Who/What buttons in the application. Moreover, the table holds the file name of the photo and the path where it is stored. The *userID* is a foreign key which links the table to the **User table** with the users‟ login credentials. This provides users privacy as they can only see their own pictures.

The **setupQuestions table** contains the images of the different description buttons as well as the text that is read out when the button is pressed by people who have difficulties reading the question above the description entry field.

The **Descriptions table** holds the sentence beginnings for each description type. This was implemented to minimise the text entry required for each description.

The **Questions table** contains the questions or question fragments, which together with the description form a question. They are the questions users of the photo album can ask their conversation partners when the photo album is in question mode.

The **Picture table** holds a number of topic introductions which users of the photo album can trigger by touching the photo in order to ask their conversation partner if e.g. they would like to see some pictures or progressing to the next picture by saying e.g. “Look at this one.”.

The author has chosen to create these tables even though the setupQuestions, Questions, Desciptions and Picture tables could have been equally hard coded. However, the idea behind putting this information into a database was that

changes to the phrasing of the standard text could easily be done without having to make changes in the code.

On reflection, one limitation of the current structure of the tables Data, Questions and Descriptions is that the information relating to the Where/When/Who/ What/Feeling buttons is organised in individual columns. This means that adding or changing questions requires changes to column headers throughout the code. Therefore, it could have been beneficial to introduce an additional table listing the question words and to add its primary key as foreign key into the Data, Questions and Descriptions tables.

5.4 Platform

As the Panasonic Toughbook H1 Health was successfully used by the participants in the prototype evaluating sessions, it was also used throughout the rest of the project.

As the Panasonic Toughbook H1 Health has a Windows XP operating system, it was decided to develop a Windows application. By default, Windows XP includes Microsoft Speech, an application programming interface that enables developers to integrate speech synthesis into their applications.

5.5 Programming Language

The first prototype started off with a PPT presentation which was later enhanced by adding ActiveX control buttons. The properties of the buttons were changed as required to adapt their appearance. Code in Visual Basic for Applications (VBA)

was then linked to the buttons to trigger actions such as voice output on click-events or moving to the next page.

Although the use of PPT and VBA was very effective in the first and second PPT-prototypes, it was considered insufficient for the final version created within this project. The main reasons for this being that with VBA, the program could not have been compiled to an executable file; the end user would be required to be in possession of MS Office; the photo upload would have been difficult to implement; and the source code would have been editable by the end user either on purpose or by accident. Therefore, an alternative programming language was looked for. As the only programming knowledge the author had were the two introductory modules to C++ of the MSc Applied Computing program, a related but more interface-orientated programming language was selected – C#. Using the high-level programming language C# had the advantage that Visual Studio 2008, an integrated development environment form Microsoft, could be used. Particularly useful was the included forms designer for building graphical user interface applications.

5.6 Database

MS Office Access was chosen as database management system as it required no additional infrastructure (e.g. a database server) apart from the freely available MS Access Runtime. Furthermore, it does not require the user to be online while using The Talking Photo Album application which was considered of advantage as users can not be assumed to have internet access, e.g. in care homes.

5.7 Code Overview

The final version of the photo album created within this project consists of the screens: Login screen, Options screen, Photo Upload screen, Setup screen and Photo Album screen. In the C# code each screen is represented by a form. The following excerpt (Figure 21) is taken from the Photo Album screen. The *speak* function combines two parts of text, i.e. the standard beginning of a photo description and the individual description entered by the user. In the event of the *Question button* being pressed, the two parts of text being combined are the question beginning and the referral to the picture such as in the case of the *Where button* “Have you been to <location of picture>?”.

```
using System.Windows.Forms;
using System.Data.OleDb; // required for connection to database
using SpeechLib; // requíred for speech output


    private void speak(DataTable part1, int columnPart1,
      DataTable part2, int columnPart2, int rowPart2)
    {
      SpVoice voice = new SpVoice();
      string text = String.Empty;
      text += part1.Rows[0].Field<string>(columnPart1) + " " +
      part2.Rows[rowPart2].Field<string>(columnPart2);
      voice.Speak(text, SpeechVoiceSpeakFlags.SVSFDefault);
    }




    private void btnWhere_Click(object sender, EventArgs e)
    {
        if (selectQuestion == true)
        {
          speak(tblQuestions, 1, tblData, 3, r);
          btnQuestion.BackgroundImage =
          global::frScratch3.Properties.Resources.Question;
          selectQuestion = false;
        }
        else
        {
          speak(tblDescriptions, 1, tblData, 3, r);
        }



    }
```

Figure 21: Code excerpt from the photo album screen.

As the photo album application requires access to the database in a number of different situations, the class *accessDB* was created to avoid repetition of code (see Figure 22). To retrieve data from the database, objects available in Visual Studio such as *OleDbCommand, OleDbCommand* and *OleDbDataAdapter* were used.

```
public class accessDB
{

[...]

  public DataSet getDataSet
  {
    get
    {
      DataSet myDS = new DataSet();


       if (File.Exists(strFile))
       {
         OleDbConnection myConn = new OleDbConnection();
                                  // instantiates connection object
         myConn.ConnectionString = "Provider=" +
         "Microsoft.Jet.OLEDB.4.0;Data Source="
                                  // provider for MS Access DB
         + strFile + ";";
         myConn.Open();// opens the connection to the
                                     database
         OleDbCommand myCMD = new OleDbCommand();
                                  // instantiates command object
         myCMD.CommandText = strQuery;
         myCMD.Connection = myConn;
                                  // specify connection for command
                                     to retrieve data
         OleDbDataAdapter myAdapter = new OleDbDataAdapter();
                                  // prepare DataAdapter
         myAdapter.SelectCommand = myCMD;
                                  // connects DataAdapter to command
                                     object
         myAdapter.Fill(myDS, "Data");
                                  // fills the DataSet with data from
                                     the database
         myConn.Close();// closes the connection to the
                                     database
       }
       return myDS;



    }
  }

}
```

Figure 22: Method to retrieve data from the database.

6 Testing

Testing is performed with the intention of finding errors in software and is consequently a prerequisite to their elimination, which in turn is vital when striving for software of high quality. There are different testing techniques each looking at different aspects of the software program. For The Talking Photo Album, Black Box Testing and White Box Testing have been undertaken at the different levels of the system. Tests such as unit testing, integration and system testing, usability testing and acceptance testing were completed as part of the iterative life-cycle. In the following, the testing techniques employed are described in more detail.

6.1 Testing Techniques

White Box Testing is based on the source code of a program and therefore requires a knowledgeable tester. It intends to find faults in the program structure and is therefore also referred to as Structural Testing. The tester has to ensure that every line of code is executed at least once, i.e. all possible ways through the code using the conditional statements, loops, and Boolean data types (Agarwal et al., 2010, Spillner et al., 2007). White Box Testing helped the developer to eliminate typographical and logical errors as well as redundant code. Moreover, it was employed to confirm that data was transferred correctly to and from the database.

In **Black Box Testing** the source code, as the name suggests, is treated as a "black box" and only input and output are considered. It could therefore be performed by a tester with no programming knowledge. Black Box Testing is based on the functional requirement specifications which is why it is also referred to as Functional Testing. For The Talking Photo Album, Black Box Testing was

primarily performed by the developer when testing the application before performing the cognitive walk-throughs with the participants.

For The Talking Photo Album **walk-throughs,** a form of group meetings with the intention to find problems but not to solve them, were also performed. The main reason for this choice was that in contrast to other methods, such as technical reviews, no preparation from the user groups was required. A walk-through was conducted for both PPT-prototypes and for the final C#-version. In individual sessions, the author presented the application to each user and their support staff while stepping through each screen of the application. The intention of this task was to communicate information about each screen to the user as well as to discover defects. Furthermore, the walk-through served as preparation for the heuristic evaluation which will be discussed at the end of this chapter.

6.2 Summative Evaluation

In a commercial software development project, acceptance testing is commonly performed by the customers when receiving the end-product from the developers. As the Talking Photo Album was developed as part of a research project, this was not possible. Instead, acceptance testing took the shape of a summative evaluation.

A person with CCN who had not previously been involved in the project conducted a heuristic evaluation according to the 10 usability principles (the “heuristics”) by Nielsen (2010a). The explanation for each heuristic can be found in Appendix 5.

Figure 23: The final prototype of The Talking Photo Album on the Toughbook.

The results of this systematic inspection were as follows:

1. **Visibility of system status**

   The evaluator pointed out that at the start of the photo album application, they felt a bit lost as there was no introduction how to use the photo album.

2. **Match between system and the real world**

   The Talking Photo Album was considered to speak the users‟ language with the words and symbols that were chosen.

3. User control and freedom

The evaluator found that even though it was possible to undo/redo e.g. picture descriptions, it was not obvious for the novice user without consulting the manual (that was still to be developed at the time of the evaluation).

4. Consistency and standards

This heuristic was considered to be fully met – words/symbols and actions were the same across all pages.

5. Error prevention

According to the evaluator the exit button could be enhanced with a question of some sort that asks the user whether they are sure they want to quit the application in order to avoid unintentional closure of the program.

6. Recognition rather than recall

The system was regarded as easy to memorize, but for the sake of completeness a list of instructions were found to be helpful.

7. Flexibility and efficiency of use

This heuristic was considered as fully met.

8. Aesthetic and minimalist design

The design was found appealing containing no irrelevant information.

9. Help users recognize, diagnose, and recover from errors

Error messages were considered to be in plain language and easy to understand. It was pointed out that a help button might be helpful.

10. Help and documentation

The evaluator was not provided with a user guide for the application as it did not exist yet at the time of the evaluation. The idea of such a booklet was given favourable opinion.

7 Conclusions

7.1 Summary

In the creation of The Talking Photo Album, people with CCN and their support workers were involved from the very beginning of the project. The project title "Participation of People with Complex Communication Needs in Designing Assistive Technology Software for Information Sharing" was formulated vaguely on purpose as the participants of the study should be involved in identifying the project remit. Keeping Prior‟s (2010b) guidelines in mind, the product idea was found with the help of informal semi-structured interviews. Market research was undertaken to see what was currently on the market and to evaluate one of the commercially available talking photo albums. In co-design sessions, user interface prototypes were built by the participants and the suitability of a touch-screen with audio symbol buttons evaluated through a Wizard of Oz experiment. The evaluation of two PPT-prototypes and a usability button game through the participants followed to arrive at a user-friendly interface and an application that allowed interactive conversation between the photo album user and their conversation partner. The Talking Photo Album was implemented in C# and included an MS Office Access database to upload and store the photos and manage their descriptions (see Figure 24) . At the end of the study a heuristic evaluation was performed through one of the participants with CCN. To conclude, the aim to develop a software system for and with adults with severe disabilities that would allow them to share information was achieved.

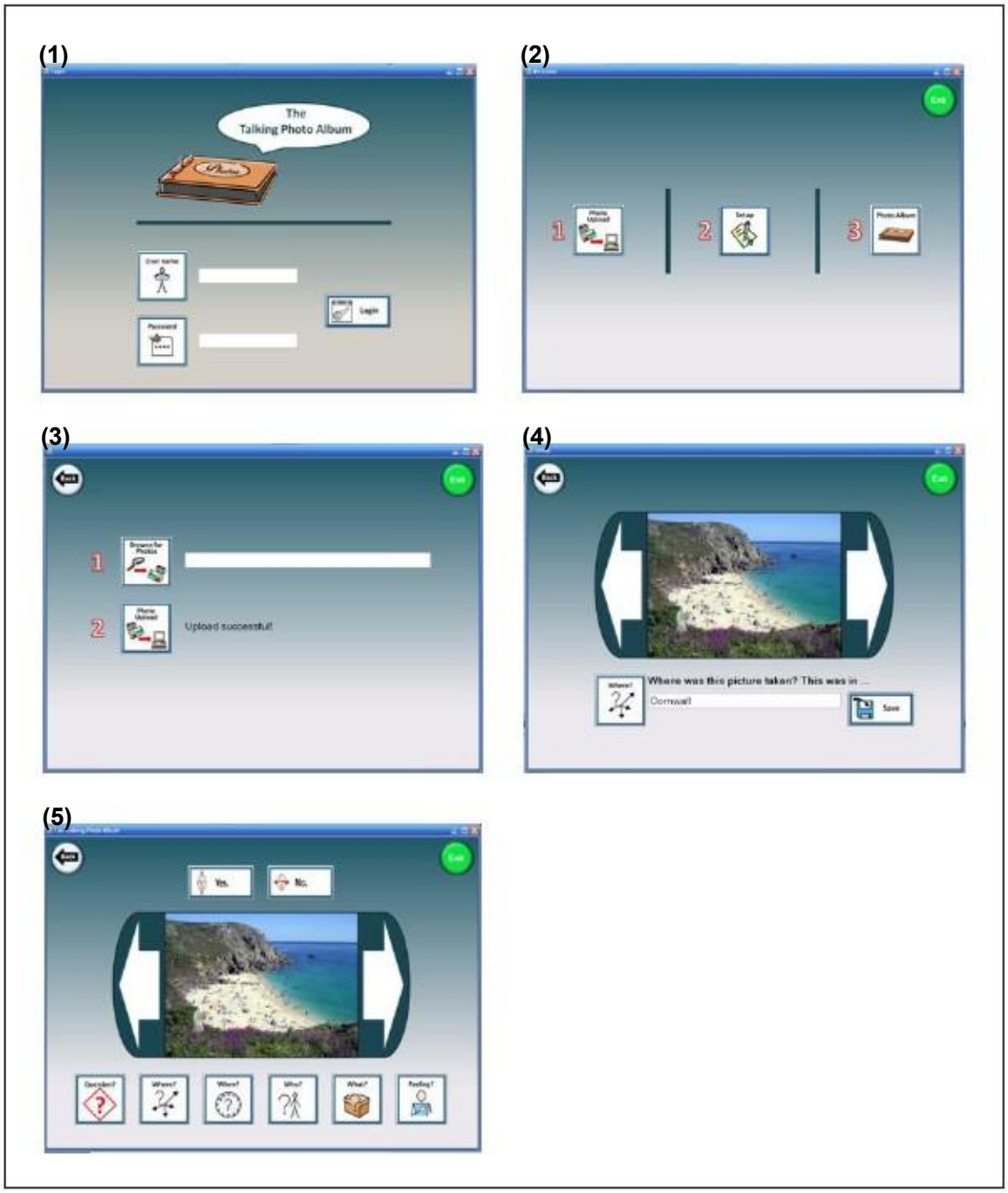

Figure 24: Final C# version of The Talking Photo Album.

7.2 Critical Appraisal of the Project

This project demonstrated successfully that participatory design methods can be used with people with CCN. It is suggested that this method should be used more

often to develop software applications for users with CCN as this may help to develop software and devices that will meet their needs more precisely and that will not be abandoned. It also became clear that there is a need to develop software and devices that enable users with CCN to share life-experiences, i.e. communication that goes beyond the exchange of basic information.

On the administrative side of the project, it would have been beneficial to request contact details from the participants right from the start to organise sessions with their support worker directly rather than through their speech and language therapist who provided the initial contact.

The programming language C#, which was used to develop The Talking Photo Album, proved to be a very versatile programming language to create user interfaces and in particular to customise buttons even though the author was not familiar with C# before starting the project.

Two features which were not implemented due to time constraints but which would clearly complete The Talking Photo Album at its current state are a delete and a user account generation facility.

The user sessions were a valuable experience for the author although getting the balance between a spontaneous flow and predetermined structure right was sometimes challenging.

Furthermore, it should be noted that the author had the impression that the participants enjoyed to be consulted and being actively involved in the study. This made it fun and rewarding for the author to work with them. Following the invitation

of the author, there was a large attendance of participants at the public demonstration of the software created during the project (Figure 25).

Figure 25: Presentation of the master project with participants and support workers listening.

7.3 Recommendation for Future Work

With an increasing amount of photos in the photo album, the need for a photo organisation facility is like to arise. A possibility could be a screen with a bookcase and different photo album which could be viewed and maintained separately. Another useful addition to the photo album might be a tag and search facility to facilitate retrieving photos to a particular key word.

Other improvements could be an alternative information input for the photo descriptions through voice recordings or a multiple photo upload.

Last but not least, a mobile version of The Talking Photo Album would enable the use on pocket-size devices like mobile phones.

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9 List of Appendices

Appendix 1: Project plan with risk analysis and mitigation possibilities.

Appendix 2: A3 poster outlining the project idea in symbols.

Appendix 3: Project summary.

Appendix 4: Evaluation questionnaire for prototype #1 and #2 and the usability button game.

Appendix 5: Nielsen‟s 10 Usability Heuristics.

Appendix G. Search Strings Used

User Centred Design and Communication Impairment*

User Centred Design AND Communication Impairment*

User Centred Design AND Severe Speech and Physical Impairments

User Centred Design AND Severe Speech and Physical Impairment*

User Centred Design AND Speech Impairment*

User Centred Design AND Speech Disability*

User Centred Design AND Communication Disability*

User Centred Design AND Cerebral Palsy

Participatory Design and Communication Impairment*

Participatory Design AND Communication Impairment*

Participatory Design AND Severe Speech and Physical Impairments

Participatory Design AND Severe Speech and Physical Impairment*

Participatory Design AND Speech Impairment*

Participatory Design AND Speech Disability*

Participatory Design AND Communication Disability*

Participatory Design AND Cerebral Palsy

Co Design and Communication Impairment*

Co Design AND Communication Impairment*

Co Design AND Severe Speech and Physical Impairments

Co Design AND Severe Speech and Physical Impairment*

Co Design AND Speech Impairment*

Co Design AND Speech Disability*

Co Design AND Communication Disability*

Co Design AND Cerebral Palsy

Appendix H. Description of Studies in Literature Review

Paper	Number of Participants	Software Being Developed
(Waller et al., 2009)	9 Children with Cerebral Palsy	Joke generating software
(Dunlop et al., 2002)	1 Participant with Cerebral Palsy	Digital Library
(O'Connor et al., 2006)	1 Participant with SSPI	Video Software
(Steriadis and Constantinou, 2003)	3 quadriplegic adults	Software to control motor movements
(McGrenere et al., 2003)	1 Participant with Aphasia	Diary Software
(Tee et al., 2005)	9 Adults with Aphasia	Cookery Software
(Allen et al., 2007)	5 Participants with Aphasia	Image Communication Application
(Visser et al., 2008)	Not Available	Graphic Symbols
(Light et al., 2007)	6 Children with SSPI	AAC Device
(Boyd-Graber et al., 2006)	9 Participants with Aphasia	Desktop PDA
(Allen, 2005)	Not Available	Portland Communication Aid
(McCoy et al., 1997)	Not Available	Intelligent AAC Device
(Hornof, 2008)	2 Children with Cerebral Palsy	Communication Software
(Davies et al., 2004)	1 Teenager with Aphasia	PDA Communication Device
(Hengeveld et al., 2008b)	12 Children with Cerebral Palsy	Educational Software

Appendix I. Requirements

Session Requirement made	Name of Requirement	Functional Requirement	Design Requirement	Suggested by Participant	Suggested By Researcher
Paper prototyping	Put in voice synthesis	*		*	
Paper prototyping	Use eye gaze	*		*	
Paper prototyping	Allow videos, text and photographs to all be stored for the same information object	*		*	
Paper prototyping	Change wording on questions		*	*	
Paper prototyping	Have symbols on buttons		*	*	
Clicker5 prototyping	Alter voice synthesis	*		*	
Clicker5 prototyping	Get rid of back button in questionnaire	*			*
Clicker5 prototyping	Just press yes/no to move through questions	*		*	
Clicker5 prototyping	Use AAC device as keyboard	*		*	
Clicker5 prototyping	Change wording on questions		*	*	
Clicker5 prototyping	Stop it interfering with other buttons on screen		*		*
Clicker5	Make buttons large		*		*

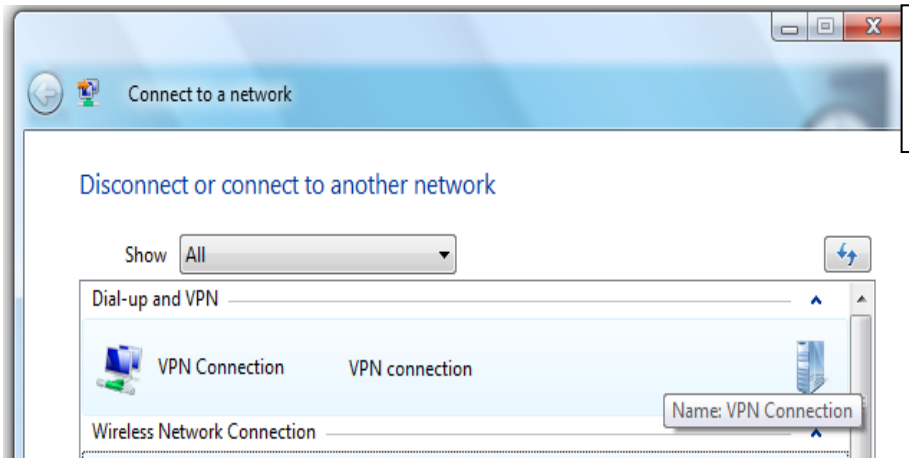
prototyping	and centred				
Clicker5 prototyping	Have symbols on buttons		*	*	
Visual Studio prototyping	Swap between symbols	*		*	
Visual Studio prototyping	Change scanning speed	*		*	
Visual Studio prototyping	Use less “cartoon” like drawings		*	*	
Visual Studio prototyping	Allow changes on staff who can see information	*		*	
Visual Studio prototyping	Make all buttons the same size and improve consistency in the software		*		*
Visual Studio prototyping	Change voice synthesiser used	*		*	
Visual Studio prototyping	Change wording on some buttons		*	*	
Visual Studio prototyping	Allow user to choose whether instructions should be read out	*		*	

Appendix J. Evaluations

Testing Champion

Connect to Computing Network

Click on the symbol marked in red. Then click on the connect or disconnect

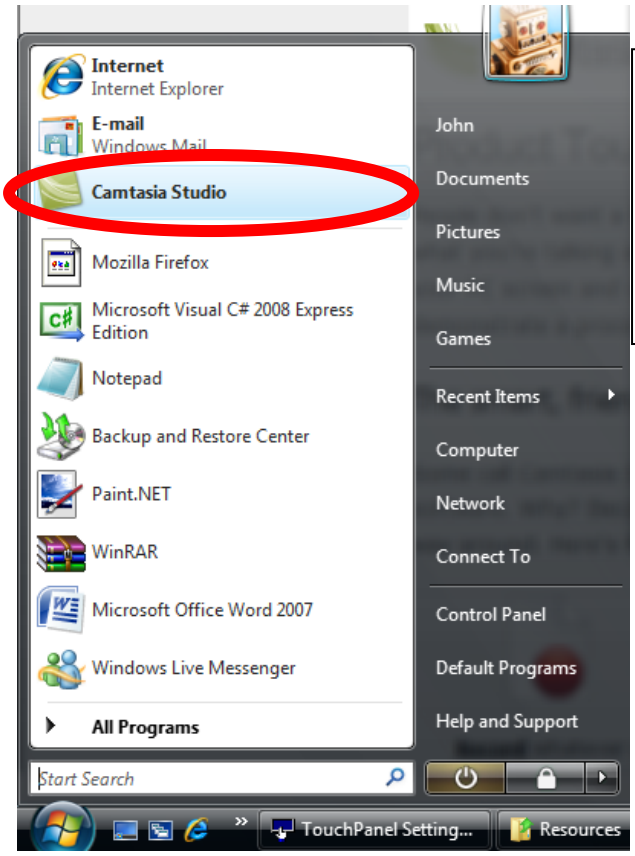


Double Click on VPN Connection

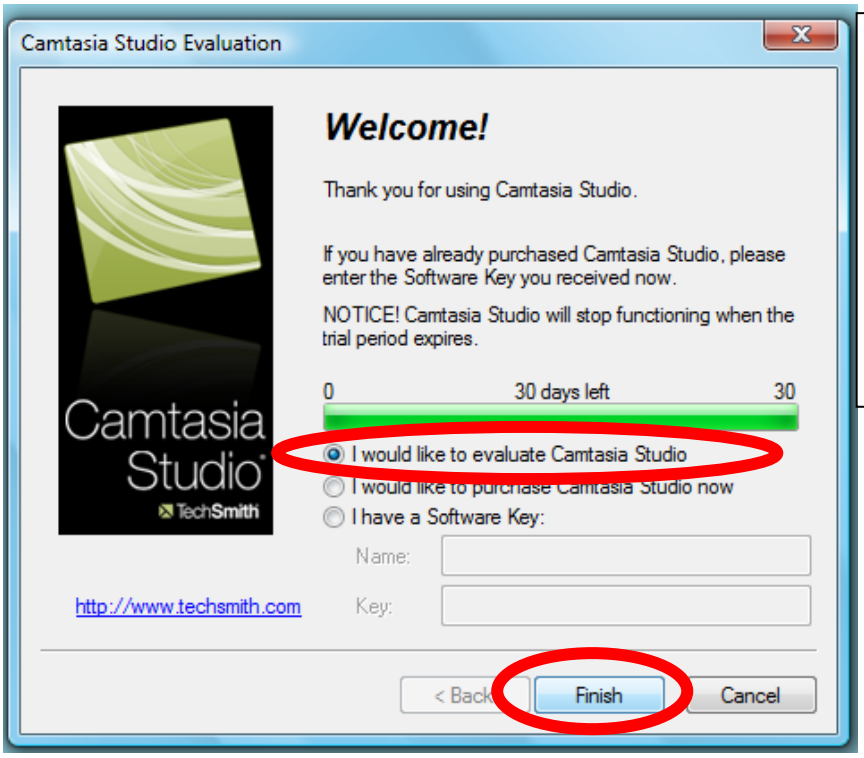
DO NOT change anything in this box. Click Connect

Double Click on VPN Connection

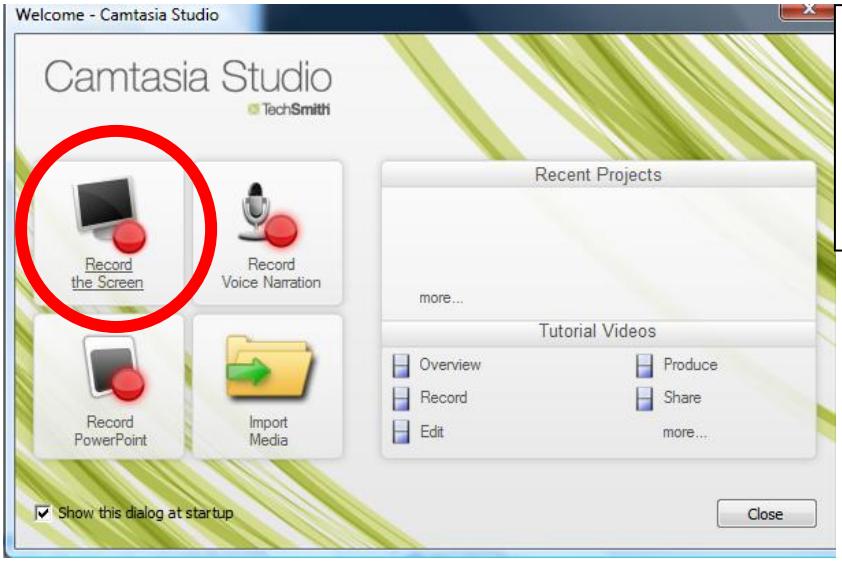
Record the Screen



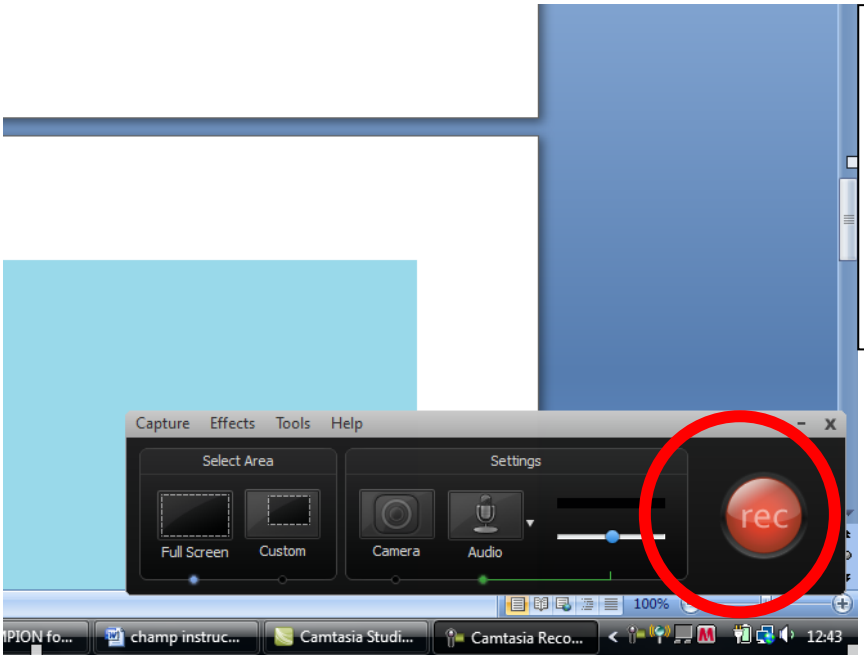
Click on the Start Button. From the menu select the Camtasia Studio program



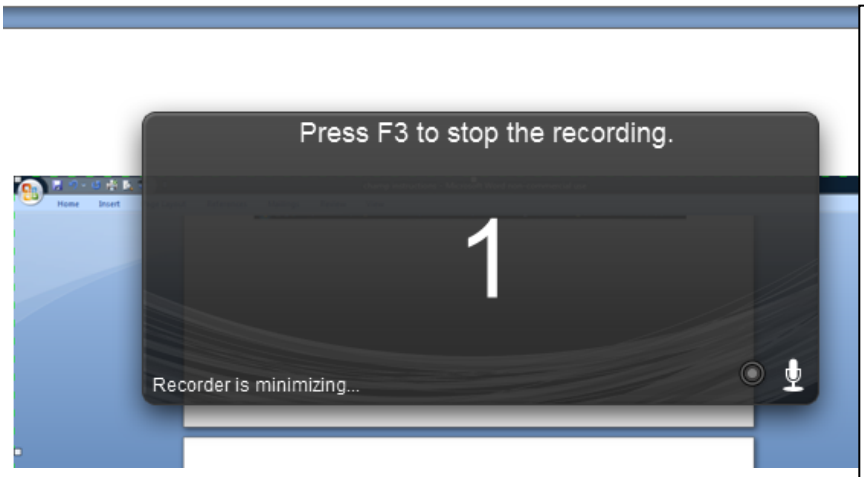
When this option appears, ensure that the "I would like the evaluate Camtasia Studio" option is selected and press Finish.



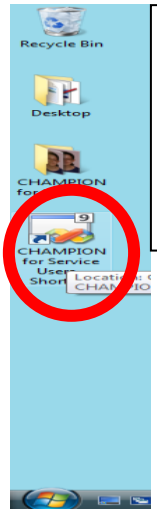
Once Camtasia is loaded please select the "Record the screen" option



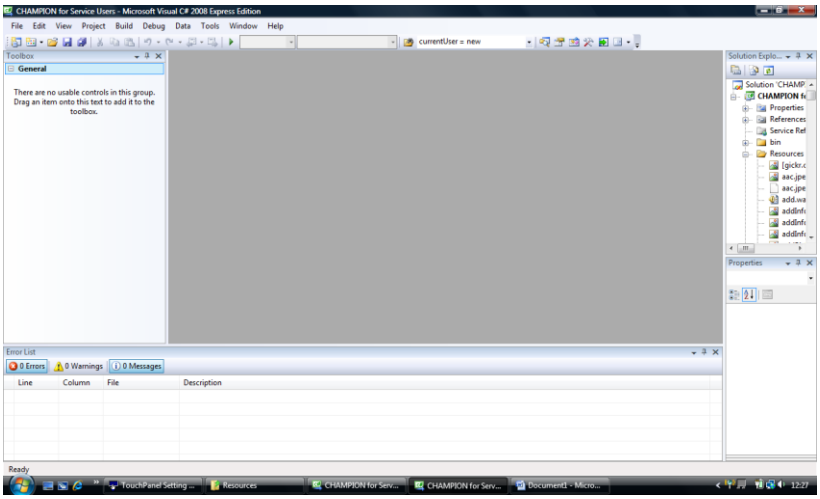
This black box will now appear, Press the red record button to begin recording the screen



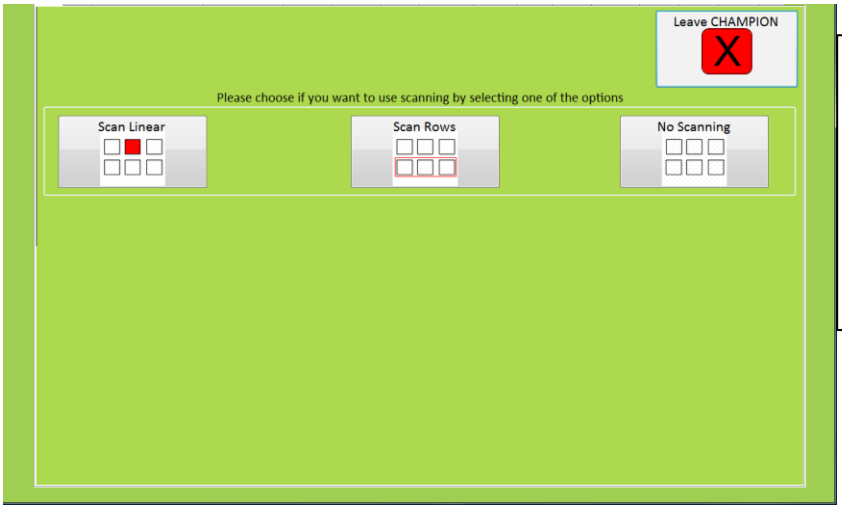
A countdown box will now appear. Wait until this has disappeared and then continue. It is important **not** to press F3 during recording as this will stop the recording.



You can now start Champion. Click this icon on the desktop



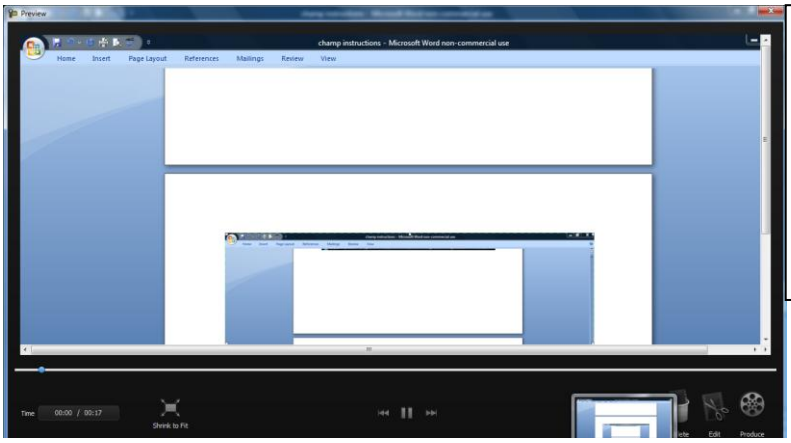
This window will appear when the program running Champion is loaded. Please press **F5** to start Champion



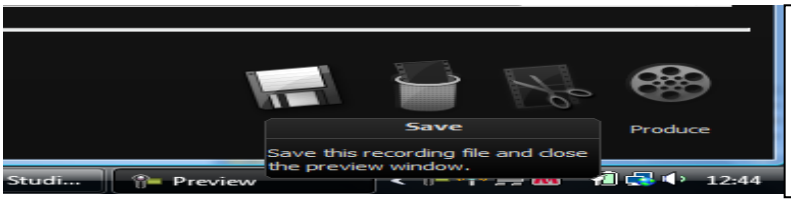
Champion will now start and you can use it to carry out the tasks you are wanting to do.

Ending the session

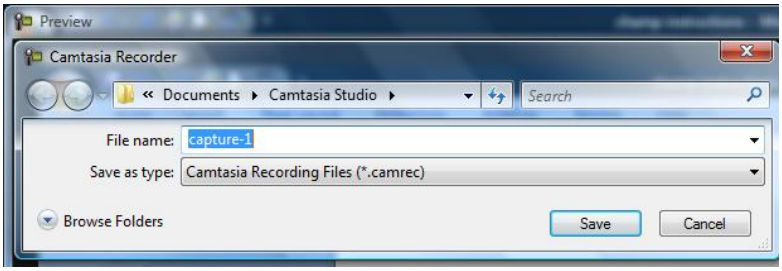
Once you have finished using Champion and have exited the program. Press F3 to stop recording and save your recording.



A preview box will now appear with a recording showing what you did during your session. You do not have to watch all of this.



Click on Save to store this recording



Please save the recording with todays date (in the form 12January etc) and the users name

Thank you for evaluating CHAMPION if there is anything you would like to tell me about using the program, please have it written down in the Champion notebook.

Any problems with the software please contact Suzanne on sprior@computing.dundee.ac.uk

Appendix K. Straight Talking User Centre

The vision for the first computing user centre for adults with Severe Speech and Physical Impairment (SSPI) was to allow adults with SSPI to come into a computing department and become co-designers in the development of assistive technology while also learning new IT skills. It was hoped that this would empower the adults with SSPI and provide them with an opportunity to have the experience of working and potentially give them to confidence to look for paid employment. As with the existing user centre for older adults, the centre members would have the opportunity to help develop better technology for the whole of the population with SSPI. It was hoped that having adults with SSPI in the department would also help 'normalise' their presence and help students to feel comfortable when meeting people with disabilities.

To investigate the feasibility for a user centre, a pilot study with 4 participants (3 female and 1 male) was conducted. All of the members had previously been involved in research projects within the department and were known to the research staff.

All participants had Severe Speech and Physical Impairments. Three participants used a wheelchair and the other used a walking aid. All of the participants had profound communication impairments and relied on gestures and aids to communicate. Two participants used LightWriter AAC devices, one used a paper board with words written on it and the other used gestures and eye gaze.

Three participants were accompanied by a support worker to the pilot study meetings. One participant lived in residential supported accommodation while the others lived in the community.

Members were invited to an initial meeting to discuss the aim of the group and to decide upon a name for the group. This discussion was in the form of an adapted focus group (Prior, Waller, & Kroll, To Appear). The members chose the name “Straight Talking” and one participant offered to produce a logo.

During the initial discussion, the group generated 3 aims of the group:

- -To train members in becoming “expert end users”
- -To raise awareness in wider community of AAC
- -To provide a social space for members to meet

The initial sessions included tasks such as designing the group’s website and a logo for the group on the computer.

It is anticipated that centre members will be used as evaluators in research and student projects. Before this service could be made available to students and staff the centre members needed preparation in being evaluators.

Centre members were given a lesson on conducting heuristic evaluations. It was not the intention of the session to produce heuristic evaluators but to provide them with a better understanding of how evaluations were conducted and provided them with a structure for their own evaluations.

Forum theatre techniques (Prior et al., 2008) were used to help prepare members for some of the challenges that come with being participants in student projects. Centre staff took on the role of the actor, playing a variety of different characters. Some portrayed students as being nervous about working with people with SSPI while others played students who were domineering and did not take the time needed to allow centre members to speak their views. One centre member would act the part of the evaluator while others were watching and providing suggestions on how they could deal with the student. By using forum theatre,

participants were able to discuss difficult topics in a non-threatening environment. Because the ‘students’ they were discussing were seen as fictional, the participants did not feel awkward discussing them and their views about them.

At the end of the session the suggestions that had been made for dealing with the students were written on a board and discussed further.

The members were trained in IT skills and were assisted in undertaking their European Computer Driving License (ECDL) if they wished. These initial members were also provided with training on assisting others to acquire IT skills and were encouraged to give presentations on IT tasks.

The centre has had one commission from outside the department. A visiting researcher from another university wanted access to expert disabled users in order to trial design techniques with adults with SSPI. The authors met with the researcher for 3 hours prior to the session and discussed the aims for the session. The author also ensured that the visiting researcher had realistic expectations for what they could achieve in the session.

Members of the centre worked with the researcher in a specially facilitated session, the author was present throughout the session to supervise and guide the session progress.

The first author, a software developer with experience in SSPI, acted as the centre manager and coordinated sessions and computer activities. The second and third author also assisted with sessions and administration tasks to ensure participants were able to attend the sessions.

It is anticipated that when the centre expands a support worker will also be hired to provide personal care and communication support when the centre is expanded to more members.

The next step for the centre will involve developing space within the Queen Mother Building at the School of Computing for use by adults with SSPI. Existing technology labs will need to be adapted for use by a larger group of adults with mobility impairments.

The group currently meets in the older adults user centre but this is not the ideal space for wheelchair users due to the amount of space, the height of desks etc.

Members for the centre will be recruited through local adult disability centres and the council social work department. The number of members admitted to the centre at any one time will unfortunately be restricted to ensure that personal care needs can be met and there are enough assistants available.

There will be a variety of types of sessions at the centre. Drop in sessions will allow members to come in and use the computers as they wish with help if they encounter difficulties. Education sessions will include lessons given to the group on topics of interest before the opportunity to do practical tasks on the topic with support. Topics for the education sessions will be suggested by centre members, for example, during a previous session at a day resource centre participants asked for assistance in using Facebook, however due to lack of IT facilities the time on Facebook had been very limited. The third type of session will be research sessions.

Once the centre is established and has a regular group of members who are happy in attending and comfortable in working with staff, students will be invited to meet with centre users and to work with them on course assignments during scheduled research sessions. When the user centre for older adults at the University of Dundee (Forbes, 2009) was established the number of student projects looking at older adults dramatically increased. It is anticipated that a similar effect will be seen with the user centre for adults with SSPI. Student

projects might focus on developing a piece of assistive technology or in developing a piece of technology for the general population but ensuring that it is also useable by people with SSPI.

In order to facilitate this work with students and to ensure that the users with SSPI do not become over used a system will be set up whereby students must liaise with the centre and specify the number of participants they require, the number of sessions needed and the duration of these.

Research projects by staff involving adults with SSPI could lead to the development of assistive technology which has a much lower abandonment rate than current AT and could improve the quality of life and independence by people with SSPI.

The pilot study has shown that the concept of a user centre is welcomed by members, as yet no one has turned down the offer of a place. The users are keen to engage in a variety of activities and they wish to bring their own skills to the group (e.g. through creating logos or assisting with the forum theatre).

There are still many challenges to be faced in the group including supporting a larger number of members, dealing with a wider range of abilities and ensuring continued funding

Appendix L. Guidelines

Guidelines Version 1

Introduction

Human-centred design is an approach of interactive system development that focuses specifically on making systems usable. It is a multi-disciplinary activity which incorporates human factors and ergonomics knowledge and techniques. The application of human-factors and ergonomics to interactive systems design enhances effectiveness and efficiency, improves human working conditions, and counteracts possible adverse effects of use on human health, safety and performance. Applying ergonomics to the design of systems involves taking account of human capabilities, skills and limitations and needs.

A person with Severe Speech and Physical Impairments (SSPI) will have different problems than a person with a Communication impairment which describes a disability affecting speech and language. A person with a communication impairment may have difficulties including articulation problems, fluency problems, aphasia and delays in speech (Medline Plus, 2009). SSPI encompass more than a communication disorder and include a range of physical, sensory and cognitive impairments (Balandin, 2002).

Working with adults with Severe Speech and Physical Impairments in human centred design

Scope

This standard provides guidance on conducting human-centred design with users with Severe Speech and Physical Impairments throughout the lifecycle of the development of a technology. This technology is not limited to assistive technology and could be a piece of technology for mainstream consumption. This standard is concerned with both hardware and software components of interactive systems.

This standard addresses the planning and management of human-centred design with users with SSPI. It is based upon the guidance in ISO-13407 regarding conducting human-centred design and as such does not address the specifics of the stage of the lifecycle specified in ISO-13407 but instead provides guidance on how these stages can be conducted with users with SSPI.

The main users of this standard will be those developers or researchers who will be working directly with users with SSPI. However it is beneficial for the entire development team to be aware of the issues in working with these users and how the project is addressing the issues.

Terms and definitions

For the purposes of this standard, the following terms and definitions apply.

Prototype

Representation of all or part of a product or system that, although limited in some way, can be used for evaluation

[ISO 13407:1999, definition 2.2]

Usability

Extent to which a product can be used by specified users to achieve specified goals with effectiveness, efficiency and satisfaction in a specified context of use.

[ISO 13407:1999, definition 2.3]

Effectiveness

Accuracy and completeness with which users achieve specified goals.

[ISO 9241-11:1998, definition 3.2]

Efficiency

Resources expended in relation to the accuracy and completeness with which users achieve goals.

[ISO 9241-11:1998, definition 3.3]

Satisfaction

Freedom from discomfort, and positive attitudes to the use of the project

[ISO 9241-11:1998, definition 3.4]

Context of use

Users, tasks, equipment (hardware, software and materials), and the physical and social environments in which a product is used.

[ISO 9241-11:1998, definition 3.5]

User

Individual interacting with the system.

[ISO 9241-10:1996, definition 2.2]

SSPI

Severe Speech and Physical Impairments encompass more than a communication disorder and include a range of physical, sensory and cognitive impairments (Balandin, 2002).

AAC

The general term for the methods used to aid communication by those for whom the more usual forms of communication are not sufficient. AAC can be divided into two different categories of unaided and aided. Most people who use AAC will use a combination of the two (American Speech-Language-Hearing Association, 2002).

Support Worker

This refers to any person who assists the user in their day to day lives or in using the system. This may be a person employed to assist the user or a family member.

Developer

This refers to the HCI practitioner, the software developer or the researcher who is involved in the project.

Rationale for working with users with SSPI

The number of computer users with cognitive and developmental disabilities is increasing. Examples of this include: day and residential units holding computer courses as part of the program for service users (Parsons et al., 2006) and schools for children with disabilities now have ICT lessons in their basic curriculum (Judge, 2001). In addition, as adults with developmental disabilities become more integrated into the workplace, the demand for computer software which is accessible by a wider spectrum of users is likely to increase.

However, the main use of technology by this user group remains in assistive technology and AAC devices. As with other user groups, a lack of user centred design may contribute to the poor adoption of technology (e.g., the rate of abandonment of AAC devices is reported to be as high as 53.3% (Riemer-Reiss and Wacker, 2000)). The main reasons given for abandonment or rejection of assistive technology are a lack of training for the end user and a lack of flexibility in adapting the system for the individual. Other reasons reported include a lack of confidence on the part of the user in their ability to use the system and the prohibitive costs in learning how to use the system.

It is suggested that the inclusion of end users in the design process may reduce this abandonment rate (Waller et al., 2005b)**.**

Structure of this standard

Clause outlines the problems that can occur with Severe Speech and Physical Impairments.

Clause 0 gives an overview of the technology that are used to assist people with SSPI.

Clause 0 discusses the problems that are noted when doing HCD with users with SSPI.

Clause 0 gives guidance on how to deal with these problems.

Clause □ highlights methods known to work at each stage of ISO 13407.

Problems for people with SSPI

People with SSPI may have cognitive impairment which can range from mild to severe and may have difficulty in understanding all that is being said in the conversation and the developer's questions.

People who use an AAC device for communication can produce words up to 25 times slower than those with normal verbal speech (Higginbotham et al., 2008b). The time therefore for a participant to reply, for example "Yes, that has happened to me" could take up to 2 minutes for a participant relying on AAC (Augmentative and Alternative Communication at the University of Washington, 2009). A person with dsyarthric speech may be able to produce words at the same rate as a participant without a SSPI, however the need for clarification of the response can slow down the rate at which the response is understood by the group (Hustad, 2006a).

People with SSPI are likely to become tired more quickly than the general population (Jahnsen et al., 2003a). This is attributed to "post-impairment syndrome", which means that those with SSPI will use between 3 and 5 times as much energy as those without the condition (Wood et al., 2008). Fatigue is also one of the most common and debilitating symptoms associated with Traumatic Brain Injury.

Technology to assist people with SSPI

Augmentative and Alternative Communication (AAC) is the general term for the methods used to aid communication by those for whom the usual form of communication through speech is not sufficient. AAC can be divided into the two different categories of unaided and aided. Most people who use AAC will use a combination of both (American Speech-Language-Hearing Association, 2002).

In unaided AAC systems additional equipment is not used, for example sign language, Makaton (Communication Matters, 2008) and facial expressions (Communication Matters, 2003). These systems have the benefit that they can be used anywhere and the user does not need to carry additional equipment around. However unaided AAC has the disadvantage that the communication partner needs to understand how the system works.

Aided AAC systems refer to a communication methods that involve a device – this may be electronic or paper based (e.g. a word board) – of some form which is external to the user. The device can be used to transmit or to receive messages and generally display symbols which the user selects to convey messages to listeners, for example a symbol board (Beukelman and Mirenda, 1992). A user can select a symbol, picture or in the case of literate users a selection of letters to build up a message. The main advantage of an aided device is its ability to offer potential for communication to people with SSPI for whom unaided systems require refined motor skills or cognitive load not within the user's capability (Hampson, 2006). Electronic devices also offer the potential for synthesised speech output in the case of speech generating devices.

Other assistive technology for this group may include electric scooters or wheelchairs to assist with mobility, personal organisers or reminders to assist with cognitive difficulties, screen readers, magnifiers and hearing aids to help with sensory problems and environmental controls to help them to live as independently as possible.

Problems that can occur when doing HCD with users with SSPI

Can a group of 'representative users' be gathered?

gathering a representative sample of different disabilities and needs is more challenging

How can different accessibility needs be met?

Can informed consent be gathered from participants, and if not is it possible to gain assent from the participant and informed consent from a legal guardian.

It is important to ensure that participants are aware of what they are consenting to

Some participants may have a guardian appointed who is required legally to consent to research.

How will you encourage participants to give feedback?

Participants are often uncomfortable in giving negative feedback to those who have designed the software

How will feedback be recorded?

Usual methods such as notes and audio recordings may not be suitable

Audio recordings may miss information if communication is not through a voice output machine

It is difficult to take notes if participants are communicating via eyegaze and word board

Is it necessary to provide incentives to participants?

Payments can interfere with benefit rules

What measures will be put in place after the study to allow participants to continue with new skills if they wish to?

Participants may have developed new skills during their involvement with the research and may be keen to continue with this after the project ends.

While organising future support is not the responsibility of researcher or developer, there is an ethical obligation to ensure that participants do not feel abandoned at the end of the study.

How will you report back to participants on what you used their feedback for?

The traditional methods for reporting back to participants is by writing a letter to participants thanking them for their help and explaining what stage the project is now at. This may not be suitable for users with SSPI.

How will contact be made with participants?

Recruiting end users can be a challenge in any situation, unlike traditional development advertising in local press or through local universities can be inappropriate or unlikely to reach the desired participants.

Guidance on issues for HCD and users with SSPI

Can a group of 'representative users' be gathered?

It is not difficult to gather a spectrum of different ages and a mix of genders among participants but gathering a representative sample of different disabilities and needs is more challenging.

It may be possible to use purposive or judgemental sampling to find users who cover most of main disabilities (communication impairment, mobility impairment, cognitive impairment and sensory impairment).

Developers can encourage users to consider how others whom they know with different disabilities would interact with the system.

Participants can be asked to consider talking to others about the system or to even ask them if they wish to take part in later evaluations.

By allowing different groups of participants to do later evaluations it is possible to gain as wide a range as possible.

How can different accessibility needs be met?

Conflicting requirements are already part of the user centred design process, in this situation however discussions between users and designers is unlikely to help resolve the issue.

The designers need to carefully examine the possibilities for including as many accessibility and adaptations as possible.

It may be possible to switch accessibility options on and off

Careful planning during development can often allow different adaptations to be used through the same piece of code.

Can informed consent be gathered from participants, and if not is it possible to gain assent from the participant and informed consent from a legal guardian?

By talking to participants after going through Participant Information Sheet and asking yes/no questions we can check that they understand what they are agreeing to.

It is still important to gain assent from the participants in the instance of a guardian signing. This should include questions to ensure they want to take part and know what will be happening in the process.

How will you encourage participants to give feedback?

Participants need to be encouraged to give negative feedback.

It is helpful to remind participants that you really want them to find flaws in the technology.

How will feedback be recorded?

Video can be intrusive, but careful planning can minimise this

Is it necessary to provide incentives to participants?

Methods of incentives can be through gift tokens etc, which should not interfere with benefit rules.

Participants will often volunteer to work without payment due to the enjoyment of taking part.

What measures will be put in place after the study to allow participants to continue with new skills if they wish to?

If it is possible for participants to take part in other projects then putting them in contact with the person organising these should be discussed

Researchers should discuss with the participants and their support staff what parts of the project they enjoyed most

How will you report back to participants on what you used their feedback for?

With participants with SSPI it is beneficial for them to meet with the development team and be given personal feedback on how the project has developed and how their own contributions have been used.

How will contact be made with participants?

Charities who work with people with SSPI may be willing to make the initial contact on behalf of the development team and then if participants are in agreement to put the two parties in contact.

There may be additional ethics procedures to go through with a charity and time should be allowed for this.

Example methods for stages in HCD

General Points

At the beginning of each session review the previous session, this will help any participants who were not present to be caught up on what has happened and will help participants with cognitive problems to recall what took place.

It is important to ensure that participants don't become overtired during the sessions, and to allow for extra time to facilitate breaks. Designers should remember that participants with SSPI are more likely to have illnesses than the general population and there may be times when sessions have to be cancelled or altered at short notice due to illness.

While it is important not to talk in an overly complicated or technical way with participants it is also vital that participants are not spoken to in a condescending tone and are made to feel as equals with the designer.

Understand and specify the context of use

Make contact with potential users and/or organisations who work with people with SSPI. It is important that participants become comfortable with the researcher/developer prior to the work commencing. The staff or family who spend time with participants should also meet with the researcher/developer.

Examine the ethical situation carefully, in addition to any internal ethics procedures, there may be ethics applications required by the charities or organisations involved. The local health authority may also require an ethics application depending where the sessions with the participants will be conducted and how participants will be recruited.

Spend time in the environment and understand how the technology may be used.

Requirements Gathering

Requirements for how technology could be used

Adults with SSPI may at first be hesitant in giving requirements to researchers due to previous poor experience of having people in authority/people from outside of their immediate circle listening to them. As such a group discussion for requirements may be beneficial – particularly if it can be arranged for the participants to know one another before hand. During group discussions it is important for people to have time to form answers using their communication device and not to feel rushed into answering. Participants will benefit from being given feedback on what was discussed at the end of the session in addition to the traditional summary which is sent out a later date. By feeding back immediately on what the researchers have heard, participants will know that their opinions have been listened to and taken onboard.

Requirements on how technology should operate

Participants may have trouble imagining how technology will work or trouble keeping track of what part of the process in using the technology they are currently imagining. Providing storyboards or videos on problems that currently exist and/or how the technology could possibly be used may help alleviate this. It is important not to specify exactly what the system will do, but allows participants to visualise and imagine more easily. The research/designer can show on the screen an image of the position of the process that is currently being discussed. It may be helpful to prompt for consideration of other groups.

Produce Design Solutions

Lo-fidelity prototyping can involve producing sketches of how technology will look and/or in user centred design having the participants produce sketches for how they imagine the system looking. This is not usually a suitable method of prototyping with adults with SSPI. One technique found to be successful is to create more tangible prototypes. Examples of this include making models of the device onto which components can be attached on as the participants wish, or by creating screen designs and then cutting up the buttons etc. These components can then be attached to magnets, the participants can then position the components on a magnetic board in the position they wish. It may also be beneficial to allow participants to use existing accessibility tools and simulate how they work in this situation. It is important that when showing prototypes designs are kept flexible enough to allow instant alterations.

Evaluation

Designers should consider different evaluation tools and not simply accept that evaluations can only take place through observations. Consider different evaluation tools, it may be possible for participants to be trained to perform heuristic evaluations. If support staff can be included in the evaluations and are willing to encourage participants to take part then there can be a role for them, many support workers will be used to completing diaries or logs as part of their daily routine and so an evaluation diary may work better in this situations than it does in a business environment for example.

Guidelines Version 2

Introduction

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Working with adults with Severe Speech and Physical Impairments in human centred design

Scope

This standard provides guidance on conducting human-centred design with users with Severe Speech and Physical Impairments throughout the lifecycle of the development of a technology. This technology is not limited to assistive technology and could be a piece of technology for mainstream consumption. This standard is concerned with both hardware and software components of interactive systems.

This standard addresses the planning and management of human-centred design with users with SSPI. It is based upon the guidance in ISO-13407 regarding conducting human-centred design and as such does not address the specifics of the stage of the lifecycle specified in ISO-13407 but instead provides guidance on how these stages can be conducted with users with SSPI.

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However, the main use of technology by this user group remains in assistive technology and AAC devices. As with other user groups, a lack of user centred design may contribute to the poor adoption of technology (e.g., the rate of abandonment of AAC devices is reported to be as high as 53.3% (Riemer-Reiss and Wacker, 2000)). The main reasons given for abandonment or rejection of assistive technology are a lack of training for the end user and a lack of flexibility in adapting the system for the individual. Other reasons reported include a lack of confidence on the part of the user in their ability to use the system and the prohibitive costs in learning how to use the system.

It is suggested that the inclusion of end users in the design process may reduce this abandonment rate (Waller et al., 2005b)**.**

Structure of this standard

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Participants are often uncomfortable in giving negative feedback to those who have designed the software

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Usual methods such as notes and audio recordings may not be suitable

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Is it necessary to provide incentives to participants?

Payments can interfere with benefit rules

What measures will be put in place after the study to allow participants to continue with new skills if they wish to?

Participants may have developed new skills during their involvement with the research and may be keen to continue with this after the project ends.

While organising future support is not the responsibility of researcher or developer, there is an ethical obligation to ensure that participants do not feel abandoned at the end of the study.

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The traditional methods for reporting back to participants is by writing a letter to participants thanking them for their help and explaining what stage the project is now at. This may not be suitable for users with SSPI.

How will contact be made with participants?

Recruiting end users can be a challenge in any situation, unlike traditional development advertising in local press or through local universities can be inappropriate or unlikely to reach the desired participants.

Guidance on issues for HCD and users with SSPI

Can a group of 'representative users' be gathered?

It is not difficult to gather a spectrum of different ages and a mix of genders among participants but gathering a representative sample of different disabilities and needs is more challenging.

It may be possible to use purposive or judgemental sampling to find users who cover most of main disabilities (communication impairment, mobility impairment, cognitive impairment and sensory impairment).

Developers can encourage users to consider how others whom they know with different disabilities would interact with the system.

Participants can be asked to consider talking to others about the system or to even ask them if they wish to take part in later evaluations.

By allowing different groups of participants to do later evaluations it is possible to gain as wide a range as possible.

How can different accessibility needs be met?

Conflicting requirements are already part of the user centred design process, in this situation however discussions between users and designers is unlikely to help resolve the issue.

The designers need to carefully examine the possibilities for including as many accessibility and adaptations as possible.

It may be possible to switch accessibility options on and off

Careful planning during development can often allow different adaptations to be used through the same piece of code.

Can informed consent be gathered from participants, and if not is it possible to gain assent from the participant and informed consent from a legal guardian?

By talking to participants after going through Participant Information Sheet and asking yes/no questions we can check that they understand what they are agreeing to.

It is still important to gain assent from the participants in the instance of a guardian signing. This should include questions to ensure they want to take part and know what will be happening in the process.

How will you encourage participants to give feedback?

Participants need to be encouraged to give negative feedback.

It is helpful to remind participants that you really want them to find flaws in the technology.

How will feedback be recorded?

Video can be intrusive, but careful planning can minimise this

Is it necessary to provide incentives to participants?

Methods of incentives can be through gift tokens etc, which should not interfere with benefit rules.

Participants will often volunteer to work without payment due to the enjoyment of taking part.

What measures will be put in place after the study to allow participants to continue with new skills if they wish to?

If it is possible for participants to take part in other projects then putting them in contact with the person organising these should be discussed

Researchers should discuss with the participants and their support staff what parts of the project they enjoyed most

How will you report back to participants on what you used their feedback for?

With participants with SSPI it is beneficial for them to meet with the development team and be given personal feedback on how the project has developed and how their own contributions have been used.

How will contact be made with participants?

Charities who work with people with SSPI may be willing to make the initial contact on behalf of the development team and then if participants are in agreement to put the two parties in contact.

There may be additional ethics procedures to go through with a charity and time should be allowed for this.

Example methods for stages in HCD

General Points

At the beginning of each session review the previous session, this will help any participants who were not present to be caught up on what has happened and will help participants with cognitive problems to recall what took place.

It is important to ensure that participants don't become overtired during the sessions, and to allow for extra time to facilitate breaks. Designers should remember that participants with SSPI are more likely to have illnesses than the general population and there may be times when sessions have to be cancelled or altered at short notice due to illness.

While it is important not to talk in an overly complicated or technical way with participants it is also vital that participants are not spoken to in a condescending tone and are made to feel as equals with the designer.

Understand and specify the context of use

Make contact with potential users and/or organisations who work with people with SSPI. It is important that participants become comfortable with the researcher/developer prior to the work commencing. The staff or family who spend time with participants should also meet with the researcher/developer.

Examine the ethical situation carefully, in addition to any internal ethics procedures, there may be ethics applications required by the charities or organisations involved. The local health authority may also require an ethics application depending where the sessions with the participants will be conducted and how participants will be recruited.

Spend time in the environment and understand how the technology may be used.

Requirements Gathering

Requirements for how technology could be used

Adults with SSPI may at first be hesitant in giving requirements to researchers due to previous poor experience of having people in authority/people from outside of their immediate circle listening to them. As such a group discussion for requirements may be beneficial – particularly if it can be arranged for the participants to know one another before hand. During group discussions it is important for people to have time to form answers using their communication device and not to feel rushed into answering. Participants will benefit from being given feedback on what was discussed at the end of the session in addition to the traditional summary which is sent out a later date. By feeding back immediately on what the researchers have heard, participants will know that their opinions have been listened to and taken onboard.

Requirements on how technology should operate

Participants may have trouble imagining how technology will work or trouble keeping track of what part of the process in using the technology they are currently imagining. Providing storyboards or videos on problems that currently exist and/or how the technology could possibly be used may help alleviate this. It is important not to specify exactly what the system will do, but allows participants to visualise and imagine more easily. The research/designer can show on the screen an image of the position of the process that is currently being discussed. It may be helpful to prompt for consideration of other groups.

Produce Design Solutions

Lo-fidelity prototyping can involve producing sketches of how technology will look and/or in user centred design having the participants produce sketches for how they imagine the system looking. This is not usually a suitable method of prototyping with adults with SSPI. One technique found to be successful is to create more tangible prototypes. Examples of this include making models of the device onto which components can be attached on as the participants wish, or by creating screen designs and then cutting up the buttons etc. These components can then be attached to magnets, the participants can then position the components on a magnetic board in the position they wish. It may also be beneficial to allow participants to use existing accessibility tools and simulate how they work in this situation. It is important that when showing prototypes designs are kept flexible enough to allow instant alterations.